Sincerely,

Toward a contemporary design of assisted suicide

Natsuki Hayashi

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Caution

The purpose of this thesis is not to recommend assisted suicide, nor is it to try to provide information on how to commit suicide. If you have suicidal thoughts, I strongly recommend that you reach out to healthcare professionals for help.

Design offerings shown in this book are speculative and not for commercial use.

Please respect my biased opinion on this subject matter, and do not continue reading this book if you are not comfortable with the idea of assisted suicide, self-deliverance, and reimagining the way we die.

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Introduction

We are living in a contemporary world of slow deaths. As medical technology advances, most doctors can prolong life but can't help end the life and suffering of their patients. As Dr. Kenneth Prager, a professor of medicine and chairman of the Medical Ethics Committee at Columbia University Medical Center, said, "It is getting harder to die today because of the advanced medical technology." Discussions about end-of-life care and decision-making bring up controversial and ethical issues.

In recent years, what was once a taboo subject—death and dying—has become an open discussion, and dignified death has become quite a hot topic. For example, the death café movement creates a safe place where people are encouraged to openly talk about death and dying with no agenda. This cultural shift is attributed in particular to the members of the baby boomer generation, who have witnessed the difficult lingering deaths of their parents and friends and are now considering how they would like to die.[1]

Into the World of Assisted Suicide

My parents are baby boomers. Even though they don't live in the United States, they seem to have a similar way of approaching life as many American baby boomers, especially my mother. Almost every time we speak on the phone, she talks about her retirement plan and how to manage healthcare expenses, despite the fact that she is still in good health. I admire her openness about this dark subject and that she spends a lot of time planning for the future.

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1 Dan Kadlec, "A good death: how boomers will change the world a final time," *Time*, August 14, 2013.

I remember a few years ago when I went back to Japan to see my parents, my mother took me to a nursing home. We visited her old friend who was staying in a small room with a tiny window, alone. She had Alzheimer's disease and other age-related health issues. Her children were too busy to take care of her, so they put her in a nursing home, hoping that she would get the round-the-clock care she needed. I thought the nursing home was such a sad and strange place. Elderly people were spending their last years surrounded by other elderly people, many of whom were sick or dying. They were alive but no longer seemed to enjoy living.

Just before we left the nursing home, my mother said to me,

"If I ever become like that, just kill me."

She wasn't joking. She knows exactly what she doesn't want at the end of her life and wanted me to know that. For her, losing control of herself mentally and/or physically is equal to losing the meaning of life. She would prefer to end her life peacefully before she gets to the point where she needs to stay in a hospital or nursing home, relying on the help of others or machines to do basic things like go to the bathroom or eat meals. To this day, my mother's words are engraved in my head. As I started thinking deeply about what my mother said to me, I realized I had no knowledge whatsoever about end-of-life care and choices. I knew that my mother wants to die peacefully before she loses her quality of life, but I had no clue how I could help her achieve that.

After a simple search online, I quickly realized that there are many people like my mother who believe in death with dignity, meaning that individuals deserve the right to end their lives on their own terms, without pain or suffering. Personally, I believe we all should have the option to end our lives with the help of physicians. I don't think the option is for everyone, but physician-assisted dying—whether it is called "physician-assisted death" or "physician aid in dying" or "physician-assisted suicide"—should be among the options available to patients at the end of life. So I want to use my thesis year to explore the territories of assisted suicide and design. This thesis is for my mother and people like her who want to have control over their last moments.

Each country has its own laws regarding assisted suicide. For my thesis, I wanted to focus on the United States, where the law is gradually changing. By focusing on the United States, I was able to reach out to subject matter experts and potential users to have conversations about this topic. However, I hope my design offerings inspire citizens in other countries and have an impact on people like my mother who are going to face issues relating to end of life in the coming years.

Right to Die Options in the U.S.

In the United States, we can achieve peaceful death either legally or illegally. Legally means that you apply for the physician-assisted suicide and receive the medication. Illegally means that you take matters into your own hands using information available to you. It is done often secretly and in most cases goes unnoticed by the authorities.

Legal Option

As of this report, five states legally allow assisted suicide. Oregon passed the law in 1994 followed by Washington in 2008, Vermont in 2013, and California in 2015. Montana also passed the law in 2009 that allows physicians to prescribe lethal medications to terminally ill patients via court ruling. In 2015, there were more than twenty-five states had aid-in-dying bills in the legislature. The movement is slowly but surely gaining momentum, and it is only a matter of time before the majority of U.S. states legally allow physician-prescribed suicide.

The criteria for receiving physician-prescribed suicide varies slightly from state to state, but the general requirements are that an individual must be:

- 18 years of age or older

- A resident of Oregon, Washington, Vermont, California, or Montana

- Capable of making and communicating health care decisions for him/herself

- Diagnosed with a terminal illness with only 6 months or less to live

- Able to self-administer and ingest the prescribed medication

Legal Option

If you are terminally ill but not the resident of one of these five states or don't meet all the criteria for receiving physician-prescribed suicide, there are nonprofit organizations that can provide information and support in the process of peacefully ending your life. Compassion & Choices and Final Exit Network are two such organizations. They both operate carefully within the legal boundaries, but the Final Exit Network is somewhat controversial even within the right-to-die movement. The book Final Exit by Derek Humphry is often referred to as the bible for assisted suicide. The author said this how to book is a book of love in an episode of VICE on HBO.[2]

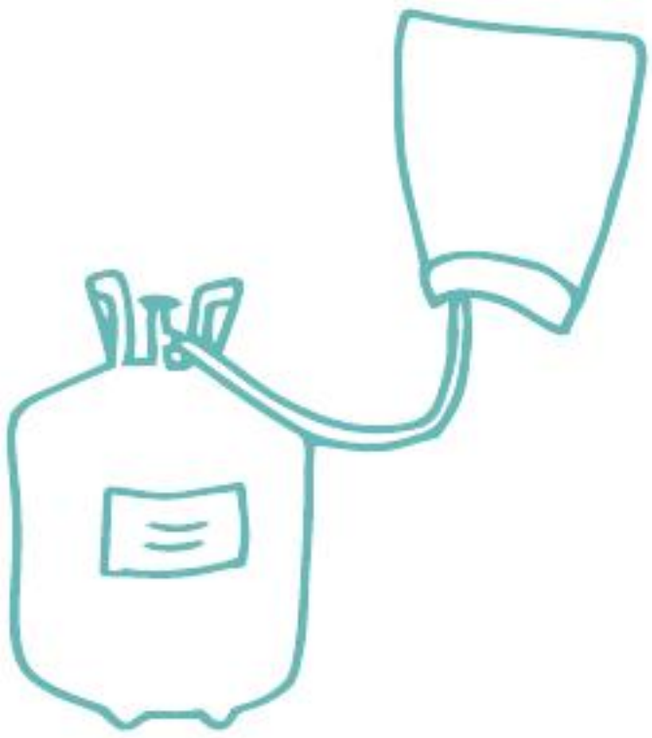
Right to Die Choices

According to Derek Humphry, a British-born American journalist known as a principal founder of the Hemlock Society USA and a pioneer in the movement for legal assisted suicide, "Today the euthanasia option—or the right to choose to die—comes in four ways:"[3]

2 Right to Die, performed by Vikram Gandhi. VICE, Season 4, Episode#3 aired on February 19, 2016.

3 Derek Humphry, Final Exit: The Practicalities of Self-deliverance and Assisted Suicide for the Dying, Third ed. (New York: Delta, 2002.) 2-3.

Passive Euthanasia is known as "pulling the plug." It is the option to disconnect life-support equipment without which patients cannot live. Medical equipment includes respirators, feeding tubes, and sophisticated drug administration. There are not many ethical debates or legal issues associated with this option as long as patients have signed a Living Will and a Durable Power of Attorney for Health Care that express their wishes to family members and physicians.



Self-deliverance is the ending-your-own-life option. This method does not involve other people directly, but patients' loved ones and friends can be, and perhaps should be, present at the time of death. It is completely legal and ethical to take your own life. When patients decide to refuse water and food, causing self-starvation and dehydration, it is also considered self-deliverance.

Physician-prescribed suicide is an option where you get lethal drugs from someone, usually a physician, and take them to cause your death. In this case, the term "assisted suicide" is often used to describe this option.

Active-euthanasia is a method involving the injection of lethal drugs. It is often done by physicians and it is illegal in most countries including the United States, even though in some cases it is necessary for doctors to carry out the procedure.

This thesis focuses mainly on the territory of self-deliverance and assisted suicide. I believe looking at the unseen world of the aid-in-dying movement, where people seek a hastening of death, informs the process of legally going through physician-assisted death and vise versa. To me, the only differences between the two are how one gets a lethal prescription from one's doctor or other sources and whether those lethal prescriptions can be obtained or not.

Times are changing, and once we open up the conversation of how we want to die, we realize that changing attitudes toward medically justified suicide are creating a growing need for access to assisted suicide or dignified death. As a designer, I want to contribute to this controversial issue. Because there is an urgency and sensitivity to this subject matter, design must do something in this area and be on top of the movement.

Goals & Objectives

Why

Death is defined as the end of life and the state of being dead, whereas dying is a process of approaching death. In recent years, we have become more open to talking about death and dying. However, there is a difference between talking about dying and talking about how we want to die. It seems there is an additional step required to be able to communicate about how, where, and when we want to end our lives. It is an extremely difficult conversation to have for both parties: people who are dying or going to die relatively soon and their close friends and family members. The nature of the subject is dark and potentially very upsetting. But we need to be able to communicate our last wishes to our loved ones before it is too late, and we need to plan and act toward that desirable end.

Today, a little more than 6 percent of the U.S. population (total population of Oregon, Washington, Vermont, California, and Montana) legally has the option to use physician-prescribed suicide to end their lives.[1] For most of us in the United States, that option is not available yet. But the law and public perception about assisted suicide are changing. Some people who need to find ways to achieve hastened peaceful death without moving to Oregon, Washington, Vermont, California, or Montana are actively seeking information and taking the matter into their own hands, even if they are at risk of breaking the law. Suicide is no longer a crime in the United States, but assisting someone to commit suicide is illegal and subject to prosecution across the country. People who deliberately

1 U.S. Census Bureau," Annual Estimates of the Resident Population: April 1, 2010 to July 1, 2014," Population Division.

support or help someone to die can be charged with murder or manslaughter depending on each state's law. Regardless of whether a person is seeking hastened death legally or illegally, the dilemma of wanting to be both law abiding and helpful to someone you love at the end of life is a muddy area where design can potentially intervene. I believe designers can play a role in reimagining the way we die and bringing light to the darkness of death and dying.

What

This thesis is the exploration into the world of assisted suicide through my personal point of view. I hope to lay out a path toward a contemporary design of assisted suicide where we can prototype and have discussions about end-of-life choices, issues, and ways in which we ultimately die.

Designing for a situation in which someone wants to end life (commit suicide) is morally very challenging if not illegal, even when that someone is terminally ill. But I see this thesis as a way to advance the discussion of death with dignity from a design perspective. I hope my work can foster meaningful conversations among people and push the boundaries of what is acceptable, legal, morally appropriate, and reasonable.

In part, this thesis is also for people like my mother who fear losing control of their lives. My work may not be an actual help to them, but at least it can show support for their end-of-life decisions.

How

In order to aid in discussions about design as it relates to end-of-life choices, issues, and the experiences of dying and reaching death, I offer a suite of design offerings that explores different perspectives on the subject.

A suite of design offerings includes a series of speculative objects, products, services, mobile applications, and experiences. These design offerings reflect my point of view about the current landscape of aid-in-dying, and imagining what it could be. The concepts were generated from a series of interviews with potential users and subject matter experts, who provided feedback on ways to improve each concept and create a new visual language around assisted suicide.

Many times, after talking to subject matter experts, I found myself wrestling with the arguments around what is legally and morally right or wrong. But I came to the realization that, at the end of the day, it all comes down to an individual's decision to call the game. While I respect everyone's opinions on the matter, when we go deep into the philosophical debate about death and dying, we go in circles. That is why I started making things. I believe by visualizing and making what is possible, plausible, and preferable in the territory of assisted suicide, we can begin to have real conversations about what we want the future to look like and work our way toward the contemporary design of assisted suicide.

I think of my process as a design investigation into the world of assisted suicide and aesthetics around the design for ending life. My design offering can be framed within a small section of the processes of legally and illegally achieved dignified death. The interventions are specific to scenarios and insights that I have generated through my research.

“Too soon is to waste the good aspects of life, and perhaps unkind to those who love and need you. Too late means you might lose control..”

– Derek Humphry, Author of Final Exit

Audience

As I mentioned previously, approximately 6 percent of the U.S. population (total population of Oregon, Washington, Vermont, California, and Montana) legally has the option to receive physician-prescribed suicide to end their life.[1] The other 94 percent of people who cannot wait for the law to change are in need of alternative ways to achieve peaceful and painless death. Death is inevitable, but self-deliverance is not for everyone. The core target users of this thesis are the terminally and irreversibly ill who want to have control over their death and plan for their last moment. It is not always the case, but ideally those patients' friends and family can be a part of the process for mental and moral support.

1 Ibid.

Terminally Ill

In order to receive a prescription for lethal medications or support from Final Exit Network or Compassion & Choices, a patient must be terminally ill. The definition of terminally ill is "with a life expectancy of six months or less to live."[2] The reason it is six months (not five or seven) is because Medicare defines terminally ill as having six months or less to live. And when you are terminally ill, you can receive Medicare hospice benefits. Medicare also states that only your hospice doctor and your primary care physician (if you have one) can certify that you're terminally ill. It is an educated prediction by doctors and there is no promise that a patient will die within six months.

2 U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Medicare hospice benefits.

Many organizations that are against physician-assisted suicide argue that it is just a doctor's prediction not fact; therefore, people can end their life prematurely.

Irreversibly Ill

Irreversible illness encompasses a wider range of diseases and conditions than terminal illness. It can be defined as 1) may be treated, but can never be cured or eliminated; 2) will leave the patient unable to care for or make decisions for him- or herself; and 3) is fatal without life-sustaining treatment or medical care. For example, Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, is a nervous system disease that weakens muscles; patients lose physical function slowly over an extended period of time. Alzheimer's disease is also considered an irreversible illness because the disease progressively destroys memory and important mental functions of patients. Right now, there is no cure for the disease.

Potential User

I find it important to describe the differences among people who choose assisted suicide because they are fundamentally different from patients who choose hospice care or palliative care. I call people who are terminally or irreversibly ill and have decided that they want to end their lives on their own terms "committers." They are not exactly patients anymore because they can't really recover to a healthy condition. Within the committers, I call people who are physically and mentally able to ingest lethal medications and carry out self-deliverance "capable committers," and people who have physical or mental difficulties taking prescriptions and committing suicide "incapable committers." Some people in the assisted suicide community use the term competent and incompetent, but I find that language sounds cold and disturbing to some degree. So, in my work, I refer them as capable and incapable.

Finding users who are thinking about going through with assisted suicide or self-deliverance, or who have gone through the process of assisting and supporting someone, proved extremely difficult for me. I tried to get in touch with patients or their family members through doctors and lawyers, but they declined because of the physician-patient and lawyer-client confidentiality. I went to online forums and tried to connect with someone online, but that also didn't lead me to an interview with an actual user. However, by talking to friends and acquaintances about what I was working on, I was able to find a few people who are considering assisted suicide in the near future. They have irreversible illnesses and have thought about death and dying quite often. I was also lucky enough to speak to a person who had assisted someone and was willing to share his experience. In addition I watched many documentary films and movies related to assisted suicide. I found myself fully immersed in those stories and used them as inspiration for my work.

A True Story

I want to share a true story of a man whom I will call Richard. He was seventy-five years old when he decided to end his life with dignity. This story is from an interview that I did with a man who was involved in Richard's plan to end his life. Because I cannot reveal his name due to legal issues associated with the event, I will call him Sam.

About Richard

Richard was a happy single gay man who'd retired from the movie business. He had no children, and his sister was his only remaining family member. He bought a loft in downtown LA back in 1972. He is the type of guy who was very much in control of his life. He didn't play around and always knew exactly what he wanted. That's why sometimes he got cranky when he couldn't get it. He was very conscious of his health, and stayed fit by going swimming three times a week. But suddenly his health started to decline and he was diagnosed with prostate cancer at the age of sixty-five. After undergoing surgeries and chemotherapy, he recovered from the disease without major complications. Soon Richard put his energy toward his passions: cultural studies and travel. He took classes, such as Middle Eastern Studies, at UCLA. He visited Middle Eastern countries for months at a time to really explore the culture while surrounded by local people.

Life seemed to be good, and Richard was enjoying life as a retiree. However, about five years ago, he felt like his cancer may have returned. This time, he decided that he would do nothing about it. He didn't want to use medical technology or advanced cancer treatments to extend his life any longer. His symptoms were manageable with some medications, so he carried on with his retirement living. He continued to take classes, and two years ago he planned a trip to Croatia for the whole month of May.

Return of Cancer

He wasn't feeling well in Croatia and came back early from his journey. He ended up in an emergency room some time later because he was having trouble breathing. That is when Sam got a call from Richard's friend. Richard's cancer had come back, this time in his throat. After getting treated in a hospital, Richard got a tracheotomy, a breathing tube in his throat. The tracheotomy meant he lost the ability to speak, and he needed assistance on a daily basis. Sam became one of his caretakers. He left work around 3 p.m., went to Richard's loft in downtown LA, and stayed with him for two to three hours every day.

Sam and Richard's other friends took shifts to take care of him. During the day, Richard had one of his friends and a nurse visit him. The nurse was there mainly to check on the medical equipment and Richard's general health. In the late afternoon Sam took over, followed by another friend in the evening. So Richard had three friends taking care of him daily. The only thing Richard actually needed help with was cleaning the little hole in his throat, nothing complicated.

Richard communicated primarily through writing. He couldn't speak, but he was still able to walk around his apartment and write what he wanted to say on a notepad. Sam and Richard usually had small chats until Richard got tired and went to rest. To Sam, it was clear that Richard was dying. He probably could have lasted months with some medical interventions here and there, but death was inevitable.

The Planning

One day in early June, Sam received a call from Richard's therapist, who had been seeing Richard for the past twenty to twenty-five years. When Sam got to Richard's apartment, everyone was there: two other friends who were taking care of Richard, the therapist, and Richard's business partner who had been around often. The therapist led the meeting by telling them to get a copy of a book called Final Exit and read it as soon as possible. The therapist expressed

Richard's wish to end his life when the time came, whenever that would be. In the end, the therapist made sure everyone agreed not to talk about this matter even with Richard himself. It was before the state of California legalized assisted suicide, so Richard had no choice but to take the matter into his own hands with the help of his friends.

Sam said it seemed that Richard picked the five people in that room intentionally and very carefully. He knew they wouldn't panic, and he knew they would all support his decision. Another interesting fact was that while they were all Richard's friends, they didn't know one another very well. After that meeting, no one talked about it again.

They knew the first thing they needed to do was to get the drugs. Richard somehow convinced his doctor to write prescriptions for liquid morphine. It seemed that wasn't strange; in fact, it is quite common for a throat cancer patient to get morphine prescriptions for pain management. So Richard had two bottles of liquid morphine sitting in the cabinet in his apartment ready to go any time. It is important to note here that Richard was not yet a hospice candidate, probably because he could have lived longer than six months. But it was also necessary for Richard to stay out of the health care system altogether because that could have complicated his exit plan.

Time Leading Up to the Day

Weeks went by, and no one mentioned anything about the plan or when the day might be. The two friends who were primarily taking care of Richard started to feel the weight of the unknown decision. One of them was Richard's health care proxy, who was in charge of taking care of his affairs including everything from managing his bank accounts and arranging a funeral home to making a list of people to contact when Richard was gone. They were not sure about the state of the relationship between Richard and his sister, but during all this, she was not involved at all. As it turns out, the therapist had previously helped someone in a similar situation and had gone through this experience once before. He was in a sense the chief architect of this plan.

The fact that the therapist made everyone agree not to talk about it made it incredibly hard for some of them. Sam and others talked on the phone, but most conversations were very practical ones. They would tell one another where they were and when they got to Richard's place or similar things of that nature. At some point, they would awkwardly ask one another whether Richard had mentioned anything about when the day might be. The pressure was building up, and the stress and exhaustion of taking care of a dying friend was getting to every one of them.

As the Fourth of July approached, Sam asked Richard if he wanted Sam to cancel his trip to San Francisco. Sam flew out to San Francisco every year around the Fourth of July with his friends, and Richard knew about his plan. Sam was more than happy to cancel the trip to stay with Richard. But Richard insisted that it was very important for Sam to go on that trip. From that one sentence, Sam knew exactly what Richard meant.

On Wednesday, July 2, Sam went to see Richard like he always did. They had a small chat; nothing seemed to have changed. When it was time for Sam to leave, Richard walked Sam to the door. Normally, Richard would stay in bed when Sam said good-bye, but that day Richard stood up and escorted Sam to

the entrance. Richard watched Sam get on the elevator and waited until the elevator door slowly closed.

That was the final goodbye between Richard and Sam. Sam went to San Francisco as he'd planned because he didn't want to raise any suspicion. But he told the other two friends to call him if they needed anything.

From here on is the story that Sam heard from the other two friends who stayed in LA with Richard.

This is the Day

Richard decided that Friday, July 4, would be the day. He thought everyone would be busy celebrating Independence Day all around the city. Around 4 p.m., Richard wrote his letter stating that this was his choice to end his life, and if anyone tried to resuscitate his body, he would sue them. The letter was based on a template from the book Final Exit. Richard had two bottles of liquid morphine. One bottle would have been enough to deeply sedate him, but just in case, he had two bottles.

A side note about liquid morphine: They got the two bottles directly from the pharmacy. One of the two had been pre-opened and used a little bit. Their assumption was that in the pharmacy, pharmacists pour out prescribed amounts of liquid morphine from a big bottle into small ones for patient use. That is why they received one sealed bottle and one pre-opened and used bottle. They assumed the quality of the contents would be the same because that was how they received the prescription.

Richard drank the entire pre-opened bottle. That should have been enough dosage to sedate him relatively quickly. One hour later, nothing had happened. . . . Everyone, including Richard himself, started panicking. They thought maybe they should just wait a little longer, and then the effects would begin to show. But still, nothing happened. The fact that the morphine wasn't doing anything made Richard extremely agitated. They couldn't really stop the process, so Richard opened the second bottle and drank the whole thing. This time, his stomach got so upset that he vomited some of the morphine backup. At that point in the process, they had no one to ask for help and needed to figure out what to do on their own.

The second bottle took effect rather quickly. Richard's body immediately started to change. After three hours of struggling with ineffective liquid morphine, Richard went into a deep sedation. Around seven to eight o'clock in the evening, they had to use a plastic bag and put it over Richard's head and neck. Richard was capable of carrying out self-deliverance (suicide). He was still able to use his hands. But because of the hole in his throat for the tracheotomy, he needed help. Covering someone's mouth and nose with a plastic bag is not that difficult. But having another hole to cover in the neck changes the circumstances dramatically. They couldn't just tie the plastic bag around his head. Somehow they needed to secure the plastic bag over the hole in Richard's neck as well. It is said that when you force a body to end life, it tries to fight to survive. "Human body doesn't want to die," Sam said.

After five hours, seventy-five-year-old Richard fell into a deep peaceful sleep and never woke up.

The next day, on Saturday morning, they came back to Richard's apartment and called 911. Detectives and forensic scientists all packed into Richard's apartment

and stayed well past eight hours conducting the investigation. It turned out the detectives were hangover, perhaps from partying the previous night, and were eager to close the investigation. They made sure to tell the police that Richard died on Saturday and not Friday because they needed to make sure that the detectives wouldn't find out the fact that they were there to help Richard. So the story they told was that when they left Richard on Friday night, he was still alive, but when they came back on Saturday morning, he was dead. That way they made it clear they were not involved in his death. Richard had arranged and paid for his funeral in advance, so all that was left to do was to follow his orders.

Looking Back at the Day

On Monday morning, Sam's phone rang. He was still in San Francisco. But he knew what this phone call was about. He learned that Richard had died on Friday night, and police had been called on Saturday. Though he knew what had happened on Friday, he didn't know what they had done with the morphine bottles or the plastic bag. He assumed they had been trashed before the police came.

The others assumed that someone addicted to morphine worked at the pharmacy and had diluted the morphine with water in order to take some for personal use. Though they would never know for sure why the first bottle of morphine hadn't worked, it had put everyone in an unexpected situation.

Richard left the majority of his money to UCLA and modest amounts to the two caregivers who took care of him most the time.

Sam told me that he was very grateful Richard had spared him from having to be there when it happened. But looking back at the whole affair, Sam said,

"The best gift Richard gave me was to be able to participate in that experience."

Sam sees life and death very differently now after being involved in this event. A man's choice to end his life changed everything he had known about death and dying. In the end, Sam believes, Richard died with dignity, and Sam is not ashamed of having helped him.

I asked Sam at the end of our interview if he would consider helping someone again, and his answer was yes. He would absolutely consider it for those he cares about deeply, and he would even consider it for himself when the time comes. Sam felt the whole thing was a lot like theater. Everyone had a role to play, and they agreed to a plan to keep the event secret. The fact that Richard's sister never knew about her brother's choice was part of Richard's plan, as was scheduling the action date on Friday and calling the police on Saturday. They all lied to the police about Richard dying on Saturday. And I'm sure there were many details that will never come to light that played a big part in creating this whole plan.

I cannot thank Sam enough for sharing his story with me and allowing me to use it as a part of my thesis work. I believe stories like this are so powerful that we should be able to share them with others without the fear of prosecution. However, today's criminal justice system forbids people like Sam from speaking up about their experiences. I hope one day Sam can share his story without having to conceal his name.

Research

I felt the need to learn about the world of assisted suicide very quickly, so early on in the process I started reaching out to subject matter experts in the fields of end-of-life care and death with dignity. I was able to speak to more than twenty experts such as lawyers, doctors, nurses, film producers, and advocates. I attended Death Café in New York City (every third Wednesday of the month) to meet people who are open to talking about death and dying. I've also read many articles, medical journals, and books related to the subject matter, and organized a workshop with family members of the elderly and terminally ill to have a discussion about death and dying. What I learned through my research has been inspiring and has become the foundation of my work.

History of Suicide and Euthanasia

In ancient Greece and Rome, before the coming of Christianity, attitudes toward euthanasia and suicide tended to be accepting. Many ancient Greeks and Romans didn't really have any particular beliefs about the inherent value of individual human lives, and it is believed that pagan physicians performed abortions and both voluntary and involuntary mercy killings frequently.[1] The word "euthanasia" comes from the Greek–eu, "good," and thanatos, "death." It literally means "good death." But the word "euthanasia" has acquired more complex and negative meaning in today's society.

1 Ian Dowbiggin, A Merciful End: The Euthanasia Movement in Modern America (New York: Oxford University Press, 2003), 2–3.

During the Middle Ages, physicians began to feel more of an obligation to care for and cure their patients, but sometimes suicide was seen as an act of heroism.[2] With the spread of Judaism and Christianity, religious thinkers opposed the idea of suicide and euthanasia as inconsistent with the human good and irresponsible in the eyes of God.[3]

The earliest American statute explicitly outlawing assisted suicide was enacted in New York in 1828, and in the same century, a criminal code that prohibited "aiding" a suicide was drafted.[4] Since then, the law itself hasn't changed much in the United States except in states where they have passed aid-in-dying laws. The major part of the debate around assisted suicide is still rooted in individual religious belief.

The Way We Die Today

What really changed is the way we die. In days of old, we died of infectious and parasitic diseases that physicians were powerless to fight. Death was often unpredictable, and the process usually lasted just a few days. Today, we are living in a world where death is predictable and occurs later in life, and in which medicine can do a lot to sustain life.[5]

Deaths have three main shapes to them: short periods of evident decline, mostly from cancer; long-term limitations with intermittent serious episodes, mostly from heart and lung failure; and prolonged dwindling, mostly from frailty and dementia.[6] In those deaths, we are dependent on family members to take care of us. Because of this world of slow death, many people have started requesting peaceful hastened death.

Now that we have a longer period of time in which we have to deal with and live with the idea of death and dying, more people are seeking a safe place where they can talk about their feelings and thoughts. For example, Death Café is a place where people can talk openly about everything related to death and dying and share their dark humor. Café Mortel (Death Café) is a concept developed by Jon Underwood, inspired by the work of Swiss sociologist Bernard Crettaz in 2010. The first Death Café was founded with the facilitation of a psychotherapist, Sue Barsky Reid (Jon Underwood's mother), in London in September 2011. Today, the Death Café movement has grown and people are hosting Death Cafés in more than twenty-nine countries. Until recently, death was something private and people didn't really talk about it, but the rise of Death Cafés is evidence of a contemporary movement that is making death more public.

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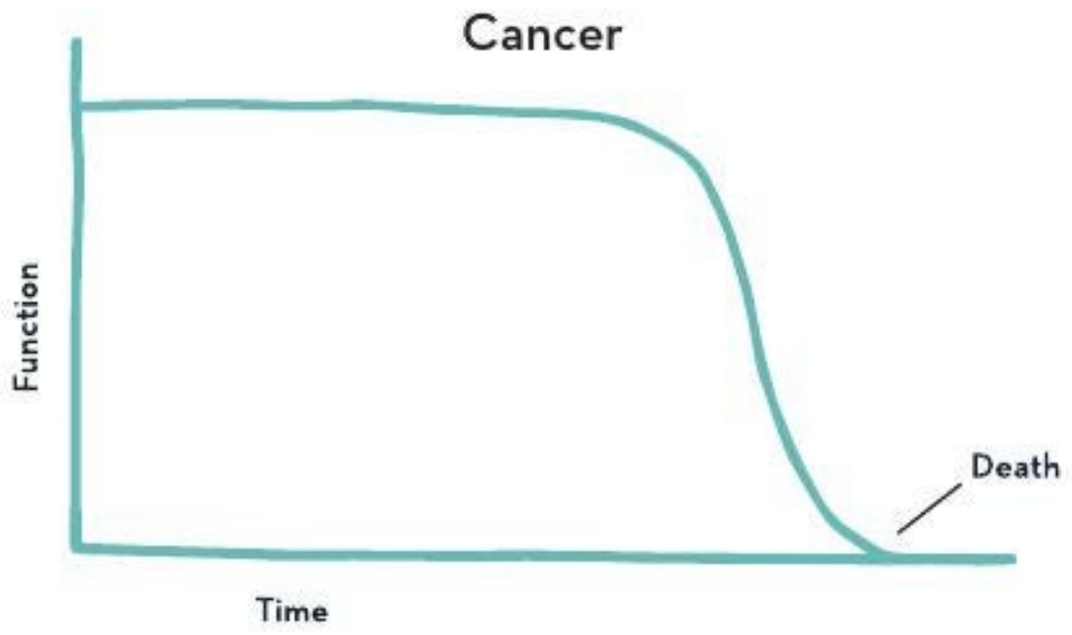
2 Marzio Barbahli, Farewell to the World: A History of Suicide (Massachusetts: Policy Press, 2015), 21.

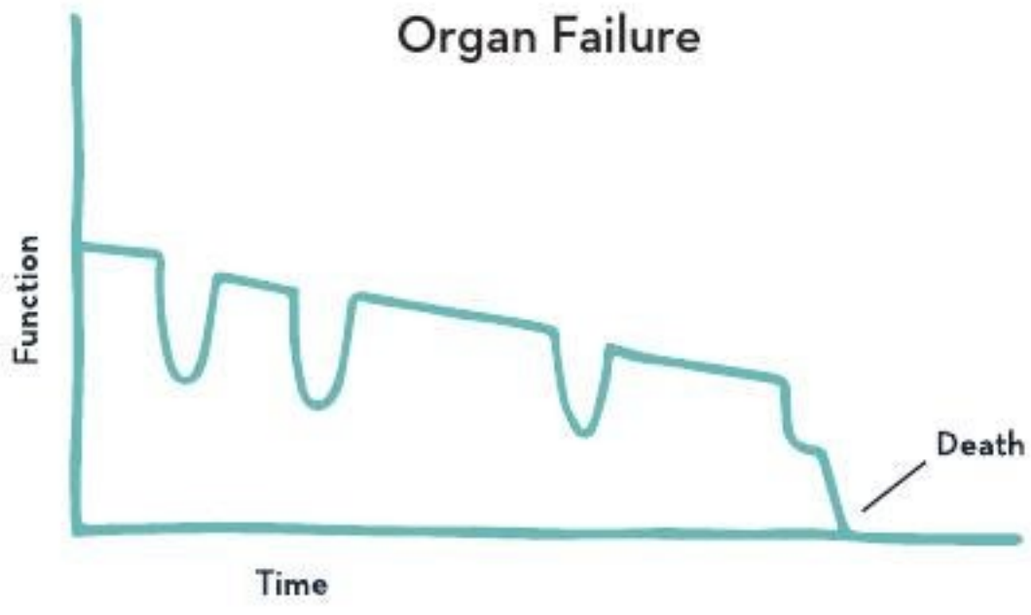
3 Ian Dowbiggin, A Concise History of Euthanasia: Life, Death, God, and Medicine (Maryland: Rowman & Littlefield, 2007), 18–19.

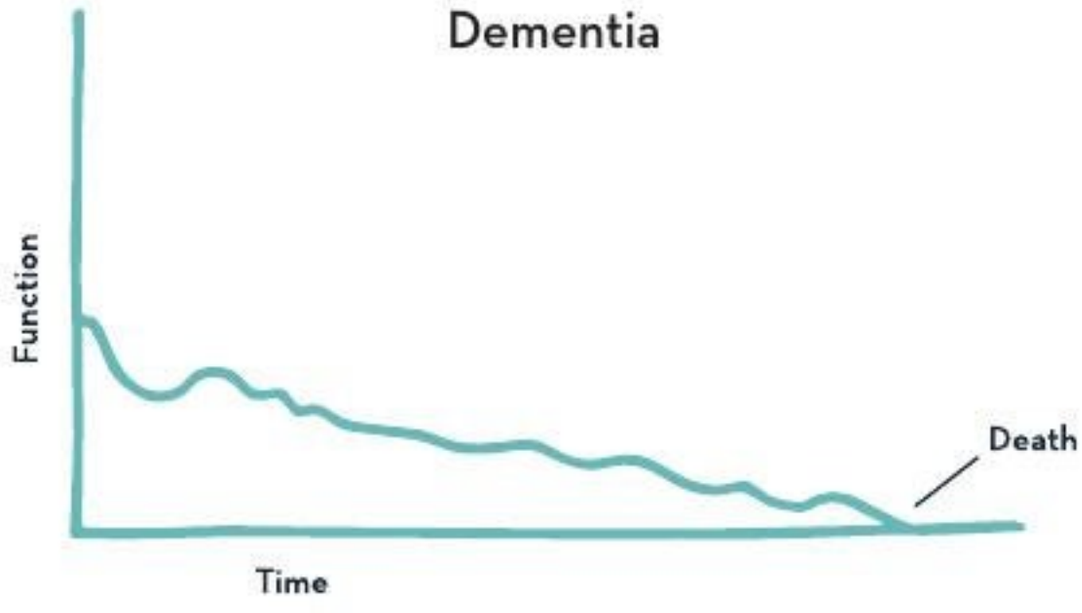
4 David C. Brody, James R. Acker and Wayne A. Logan, Criminal Law (Maryland: Aspen Publishers, 2001), 93.

5 Margaret Pabst Battin, "Choosing the Least Worst Death," TEDMED 2014.

6 Joanne Lynn and David M. Adamson, Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age, Santa Monica, CA: RAND, 2003.







Joanne Lynn, MD

I met Joel Harm, the founder of lifetrend, an app that helps patients navigate through the end-of-life options in the healthcare system, at Death Café in New York City on the third Wednesday of November 2015. He said that the current healthcare system doesn't encourage conversations around end-of-life choices. He believes that if we are able to talk about options and wishes before tragedy strikes, we can reduce pain and suffering for the patient and their loved ones drastically. I think we are at a point in history where we are realizing the need to adjust the way we die and communicate our end of life wishes to our family members and doctors.

The Legal Process

In an interview with David C. Leven, executive director of End of Life Choices New York City, I learned that the main reason that legislature is moving so slowly in the United States is because there is no compelling benefit to passing the law immediately. On top of that, funding for campaigns usually runs out very quickly. For example, during 2015, 218 people received prescriptions for lethal medications under the provisions of the Oregon Death with Dignity Act, and a reported 132 people had died from ingesting the medications prescribed under the law either from the same year or the previous year.[7] In 2013, 0.21 percent of all deaths in Oregon were due to the Death with Dignity Act, and according to the data from 2012, the rate of assisted deaths in Washington was very similar at 0.23 percent.[8] This means that a very small percentage of the population actually use the law. In the legislature's mind, therefore, there is no pressure to push that agenda forward immediately.

In the state of Oregon, the process of using the Death with Dignity Act is actually not that easy. There are many steps that people have to follow to acquire their lethal medications.

The law was designed to enable aid in dying, not to make it an easy way out.

So the majority of those who use the law are assisted by volunteers from an advocacy group called Compassion & Choices, an American nonprofit organization working to improve patient rights and individual choice at the end of life, including access to medical aid in dying. Its primary function is to advocate for and ensure access to end-of-life options, including physician-prescribed suicide. At no cost, they offer information, consultations, and various programs about end-of-life choices for dying patients and their families. In the states where physician-prescribed suicide is legal, patients' doctors can call their medical directors to have a doctor-to-doctor consultation about individual cases. Professional consultants and trained volunteers work by phone or in person to offer assistance in completing advance directives and make referrals to local services including hospice and support groups.

When patients decide that they want to take advantage of the Death with Dignity Act in the state of Oregon, they often contact Compassion & Choices for support and guidance. Their work was highlighted in the documentary film How to Die in Oregon (2011).

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7 Oregon Public Health Division, "Oregon Death with Dignity Act: 2015 Data Summary," February 4, 2016.

8 Sophie Warns, "How Many People Choose Assisted Suicide Where It Is Legal?," The Guardian, July 18, 2014.

From there, volunteers from the organization explain the process and guide them through the legal paperwork over the phone and/or in person.
The required steps are as follows:

1. The patient must make two oral requests to his/her physician, separated by at least fifteen days.

2. They must provide a written, witnessed request to the physician (two witnesses).

3. The prescribing physician and a consulting physician must confirm the diagnosis and prognosis and sign the paperwork.

4. The prescribing physician and a consulting physician must determine whether the patient is capable of administering the medication.

5. If either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder, she/he must refer the patient for a psychological examination.

6. The prescribing physician must inform the patient of feasible alternatives to assisted suicide, including comfort care, hospice care, and pain control.

7. The prescribing physician must request, but may not require, the patient to notify his next of kin of the prescription request.

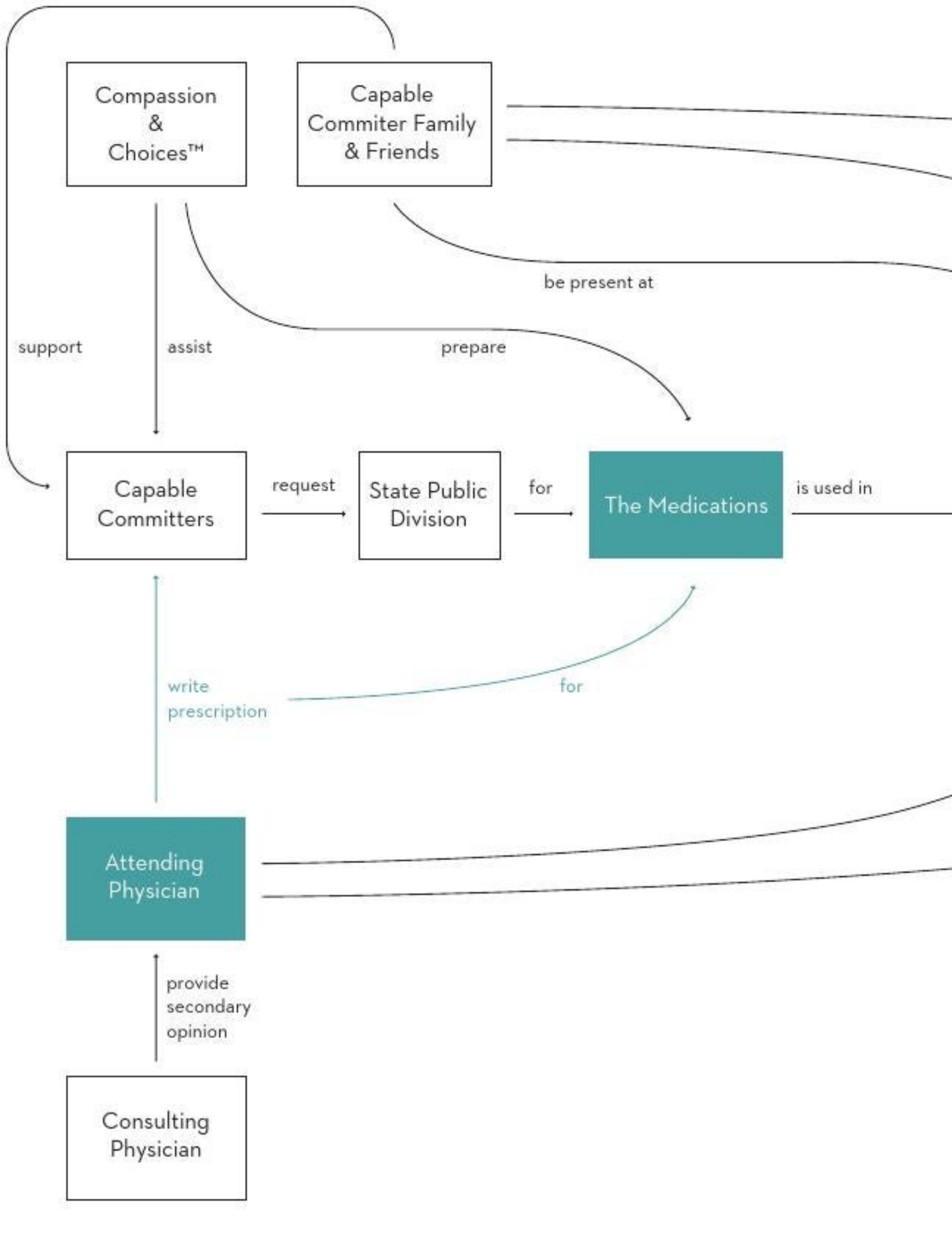
Forms needed at this stage of the process are: Patient Request Form, Attending Physician Form, Consulting Physician Form, and Psychiatrist/Psychologist Form. Volunteers from Compassion & Choices help patients fill out and process those forms alongside physicians.

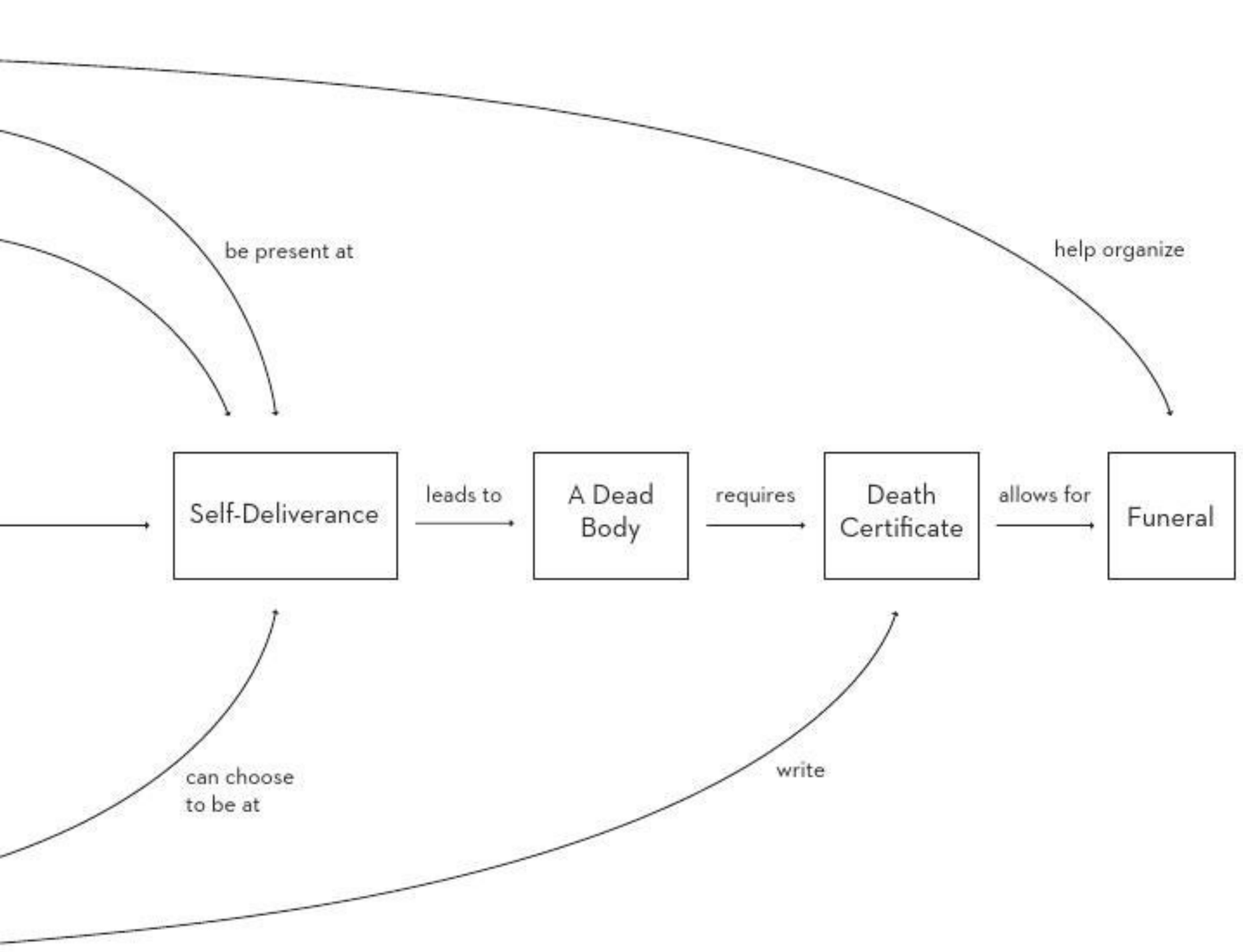
Once the request has been approved, the patient must go pick up the medication at a designated dispensing pharmacy, and the prescribing physician must report to Oregon Health Services (OHS) all prescriptions for lethal medications. (Reporting is not required if patients begin the request process but never receive a prescription.) And physicians must inform pharmacists of the prescribed medication's ultimate use. The Pharmacy Dispensing Record Form is needed to complete this process. In the state of Oregon, physicians and patients who follow the requirements are protected from criminal prosecution, and the choice of legal physician-assisted suicide cannot affect the status of a patient's health or life insurance policies because the act is not considered suicide.

Throughout this process, volunteers not only help with paperwork but mentally support patients and their family members. Those trained and experienced volunteers make sure that the patients understand their choices and the fact that they can change their mind at any time. They pay regular visits to patients' homes and talk about any concerns and feelings they may have, and they also help with requesting the right medication for their patients.

On the date that patients choose to take the medication to end their life, Compassion & Choices volunteers are present at their homes and are usually the ones who prepare the final cocktail for them. In the documentary How to Die in Oregon, all patients had a Compassion & Choices volunteer by their side throughout the process, including the last moment. While family and friends are saying their final good-byes, volunteers prepare the medication and inform the patient of the consequences of drinking the medication and ask whether

Legal Process Diagram

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they want to drink it. At the end of the process, prescribing physicians have to file the Attending Physician Follow-Up Form within ten days of a patient's death indicating whether the death was from ingestion of the lethal dose of medication obtained under the DWDA or from any other cause.

The Illegal Process

The illegal (secret) way to achieve hastened dignified death is most likely harder than legally getting a prescription and ingesting the medication. It is often complicated, and family members and friends (if they are involved) need to be extremely careful about the plan. Depending on their involvement, they are at risk of breaking the law and could be subjected to prosecution.

Final Exit Book

Today, many people who choose to end their life consult a book called Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying. A controversial work by Derek Humphry, founder of the Hemlock Society and past president of the World Federation of Right to Die Societies, it was recognized as the main resource and guide on assisted suicide in 1997. Humphry wrote the book as a how-to guide for terminally ill people who wish to end their lives. The controversy arose not only from the intense debate over whether one should have the right to end his/her own life, and whether anyone, especially medical professionals, can ethically assist self-chosen euthanasia, but also because the information in the book can be used by anyone, not just the terminally ill. He also wrote a book called Jean's Way: A Love Story, in which he shared his experience of helping his first wife, Jean, end her life with an intentional overdose of medication after a long and painful decline from terminal cancer back in 1975 in England. Final Exit covers many aspects of planning and carrying out suicide, from when a person decides he or she is ready to die and the careful protection of anyone assisting the person's preparations, to the legal and financial arrangements made for those the person leaves behind. The majority of the work addresses the advantages, disadvantages, and processes for a variety of suicide methods.

Final Exit Network

After reading Final Exit, many also reach out for the support and guidance of organizations such as Final Exit Network or Compassion & Choices. As I mentioned before, Compassion & Choices also helps people who live in states where physician-prescribed suicide is not accessible. Members from Hemlock Society, established in 1980, eventually broke off into two groups and started Compassion & Choices and Final Exit Network, each with different intentions. Compassion & Choices focuses on legislative change, whereas Final Exit Network tries to address the current and immediate needs of those who are suffering now, in a very real and personal way. Final Exit Network, Inc. is a nonprofit organization founded in 2004 by Thomas Goodwin for the purpose of serving as a resource to individuals seeking information and emotional support in committing medically justified suicide as a means to end suffering from chronically painful—though not necessarily terminal—illness. The organization is a volunteer-based institution serving members in all fifty states who are mentally competent, suffering from intolerable medical circumstances, want to end their lives, and meet their official written criteria. Those conditions include cancer, ALS (Lou Gehrig's disease), Alzheimer's disease, Huntington's disease, multiple

sclerosis, muscular dystrophy, emphysema, congestive heart failure, stroke, AIDS, and many other lesser-known but serious, frequently lengthy ailments. They offer the most current information available for self-deliverance when the member is ready to choose.

When an individual contacts the organization for help, an exit guide is assigned to him/her. The exit guide helps the person with the process of approval, gives them information on where to obtain equipment to carry out the suicide, and provides guidance on how to complete the act. The approval process is done through application forms, written essays on why an individual wants to pursue suicide as a way to end his/her life, a review of medical records by medical professionals, and a series of interviews and psychological evaluations if necessary. A final exit guide may be present at the suicide, which the network calls a "final event," to offer support to the individual and his/her loved ones. According to the Final Exit website, exit guides do not obtain equipment for individuals or participate in the act of suicide. They only provide information and emotional support, and they are present at the moment of self-deliverance if requested.

In fact, anyone who believes in the mission of the organization can join the network. Only members can be accepted into the exit guide program to receive assistance with their own self-deliverance. Membership costs $50 and proceeds are used to fund "final events," which may include interstate travel costs for the exit guide, long-distance calls, and medical oversight. However, the Exit Guide services are free to all members.

In an interview with Frank J. Kavanaugh, PhD, from Final Exit Network, I learned that Final Exit Network is the only organization in the United States that will help individuals who are not "terminally ill" (defined as having six months or less to live). No other organization in the United States makes that commitment. They accept irreversibly ill patients with conditions such as Alzheimer's, dementia, Parkinson's, and Lou Gehrig's disease. There is no cure for those diseases and the process often takes more than six months. In the case of Alzheimer's and dementia, the dying process may take more than a decade. Throughout the process, patients slowly become mentally or physically incapable of doing many simple tasks such as going to the bathroom, and eventually they lose the ability to even commit suicide. Dr. Kavanaugh has been a health educator for forty years. He retired as a professor of medical and public affairs at the George Washington University Medical Center and professor of communications with an endowed chair at George Washington University. He said that his years of experience in the medical community made him understand the tremendous advances we have made in intervening in patient's health issues and improving lives. But at the same time, all too often the medical community walks away from patients at the most critical time in their lives when nothing more can be done to relieve their suffering. And that led Kavanaugh to join the advisory board of the Final Exit Network. He told me that as an eighty-one-year-old man, he is still in good health and enjoying his retired life in Florida. But he is well prepared for the time to come. If his health suddenly starts to decline and he feels that his quality of life has decreased drastically, he will know what to do. That preparedness gives him comfort and allows him to enjoy the life that he has now.

**“Nobody should ever have to die alone.
We do not come into this world alone and
should not have to leave it alone.”**

— Fran Schindler, Exit Guide

Toward the end of our interview, I asked him if he could connect me to an exit guide. His answer was no, because all exit guides' identities need to be protected. They risk spending their lives behind bars for others and what they do for people in need should be respected. Even though I wasn't able to personally speak to an exit guide, I did listen to one on a podcast called Criminal. In the podcast, episode 17: Final Exit, the host, Phoebe Judge, interviews an elderly woman named Fran Schindler, who is known as an exit guide at Final Exit Network. She travels around the country providing information, guidance, and mental support for members who have chosen to carry out self-deliverance. She said that her role is to act as a supporter for individuals and their family members. She does not bring anything nor touch anything; she just sits with them by their bedside because she absolutely believes that "Nobody should ever have to die alone. We do not come into this world alone and should not have to leave it alone." Sometimes, her travel takes three to four days depending on the case. In some instances, she's had to have the member in need distract his or her caregiver in order for Schindler to carry out the act. She has ended up waiting at a bus stop with her colleague for hours and hours. She has visited a highly secured apartment building in New York City to provide support for an individual and family members. She said that wherever she goes, she is welcomed and instantly becomes a member of that family.

In addition to having a plan to get into someone's house or apartment to witness self-deliverance and death, she has a "discovery plan," a fully developed strategy to walk out of a person's residence while ensuring that someone discovers the body and takes care of things afterward. If that someone is not with her at that moment, she will leave the home as if she was just visiting. When Phoebe Judge asked her if she was scared of being caught, she insisted that she wasn't. If she felt scared, she wouldn't be doing what she is doing, and she believes that she is doing nothing wrong. She minimizes her risks by involving family members and allowing them to be a part of the process. Since 2007, Schindler has sat beside thirty-five people in various states who ended their lives using the information she provided them. Each year, the organization helps about twenty-five people end their journeys.[9]

Though Schindler has escaped serious consequences so far, some of her colleagues have not been as fortunate. Many have been involved in cases in which family members, unaware of the patient's decision, took legal action against Final Exit Network, often citing religious and personal beliefs against suicide.

One of their infamous cases is the suicide of John Celmer, a fifty-eight-year-old from Georgia. Celmer was diagnosed with throat and mouth cancer. According to his physicians, he had been making a "remarkable" recovery when he requested the help of Final Exit Network. He'd had trouble accepting his appearance after multiple face and neck surgeries to remove cancer left him disfigured. Four members of the Final Exit Network (former network president Thomas E. Goodwin, former medical director Dr. Lawrence D. Egbert, regional coordinator Nicholas Alec Sheridan, and member Claire Blehr) were arrested in 2009 in connection with the suicide of John Clemens after the network was infiltrated by an undercover Georgia Bureau of Investigation agent. This case started as Celmer's widow,

9 Renee Chou, "Chapel Hill Woman: 'I Will Never Leave You until You're Dead,'" Capitol Broadcasting Company, October 7, 2015.

Susan Celmer, asked for an investigation because she had strong feelings against the actions of her husband and Final Exit Network. But Celmer's mother, Betty, felt that if there were people who helped John to die, that was what he wanted and she would never find them guilty of helping him. In 2012, all the charges against Goodwin, Blehr, Egbert, and Sheridan were dismissed as Georgia's Supreme Court unanimously struck down the state's assisted-suicide law.[10]

Another interesting case involved a mentally ill but physically healthy fifty-eight-year-old woman, Jana Van Voorhis from Phoenix, Arizona. In 2007 she committed suicide in her home by inhaling helium gas under the guidance of the Final Exit Network. Wye Hale-Rowe and Frank Langsner were providing Van Voorhis support and guidance. As a result, they were both arrested and charged with manslaughter after authorities learned the nature of Van Voorhis's death. She told the Final Exit Network that she suffered from cancer and other physical ailments, but what she actually suffered from was a mental illness. After Van Voorhis's death, the two exit guides placed her body in bed to make it appear to be a natural death and disposed of the evidence of her suicide, including two helium tanks and the "exit hood." Somehow Van Voorhis managed to convince the Final Exit Network's medical professionals that she was dying of cancer. Also charged in this case were the former Final Exit Network medical director, Dr. Larry Egbert, and Roberta Massey. In 2010, Wye Hale-Rowe and Frank Langsner both pleaded guilty to facilitating manslaughter.[11]

Whether one gets guidance from Final Exit Network or not, steps to achieve peaceful death are very similar. You need to have your living will and durable power of attorney for health care, and you must communicate your wishes to your family members and close friends. Probably you will have to sort out financial statements with your lawyers as well. After that, you need to carefully select few people that you absolutely trust and let them know in advance what you are contemplating. Discretion is extremely important because you do not want everyone to know that you are going to commit suicide. It is better to include only a close circle of friends and family members who understand and support your decision.

The next step is to "shop" for the right doctor. It is recommended that you communicate with your primary doctors about your point of view on the right-to-die issue and see if they are supportive of your opinion. Then you may discuss whether they would assist by writing some prescriptions to help you achieve your goal. Otherwise, you may need to go to a doctor and keep asking him/her for a stronger sleep aid or other drugs that may lead to death if overdosed. People use medications with a plastic bag to ensure the death if the medication is not extremely lethal and fast acting, like a barbiturate. Another method that Final Exit Network often recommends is the inert gas method.

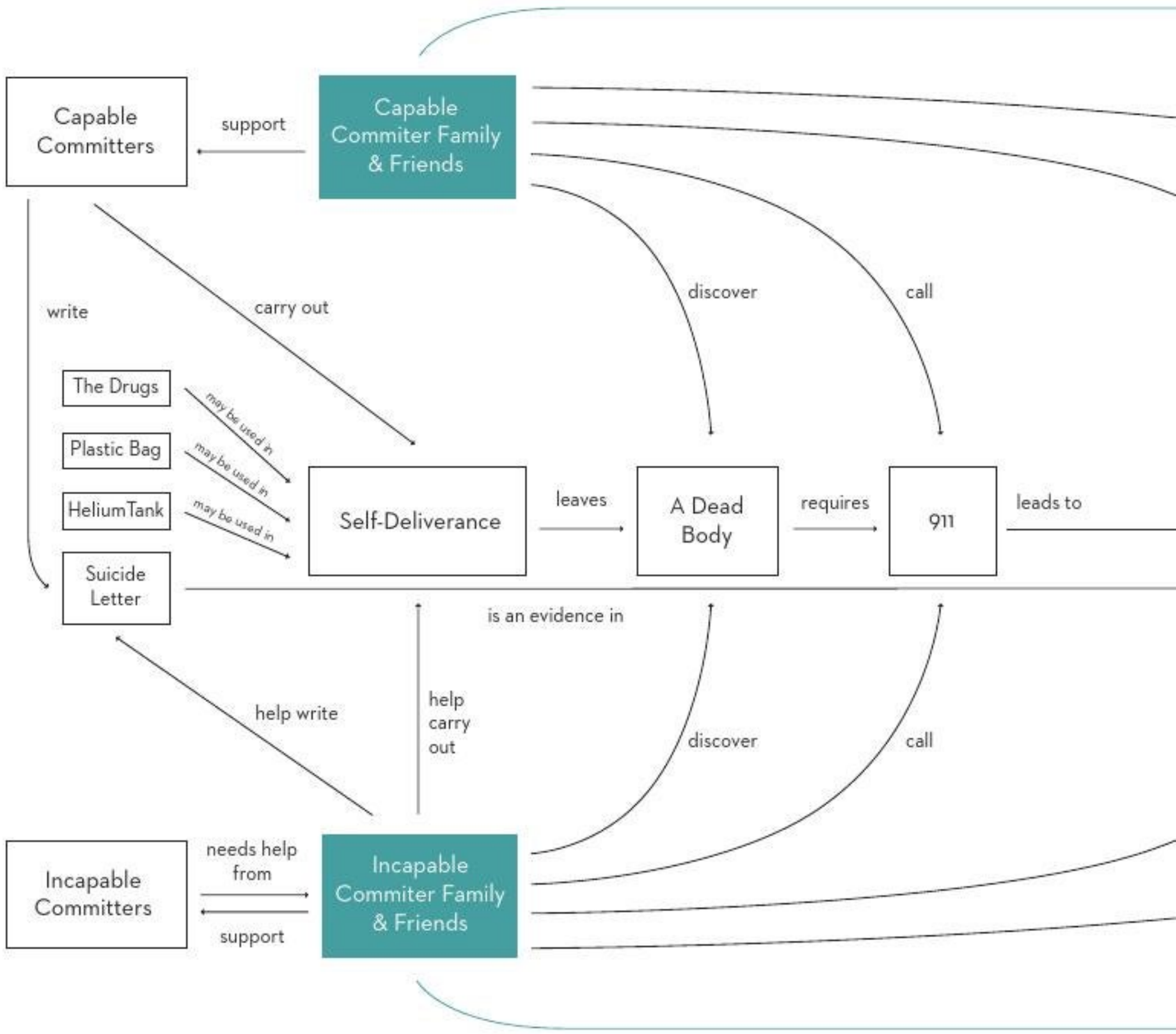
10 Ashley Hayes, "Court Strikes Down Georgia's Assisted-Suicide Law," CNN, February 6, 2012.

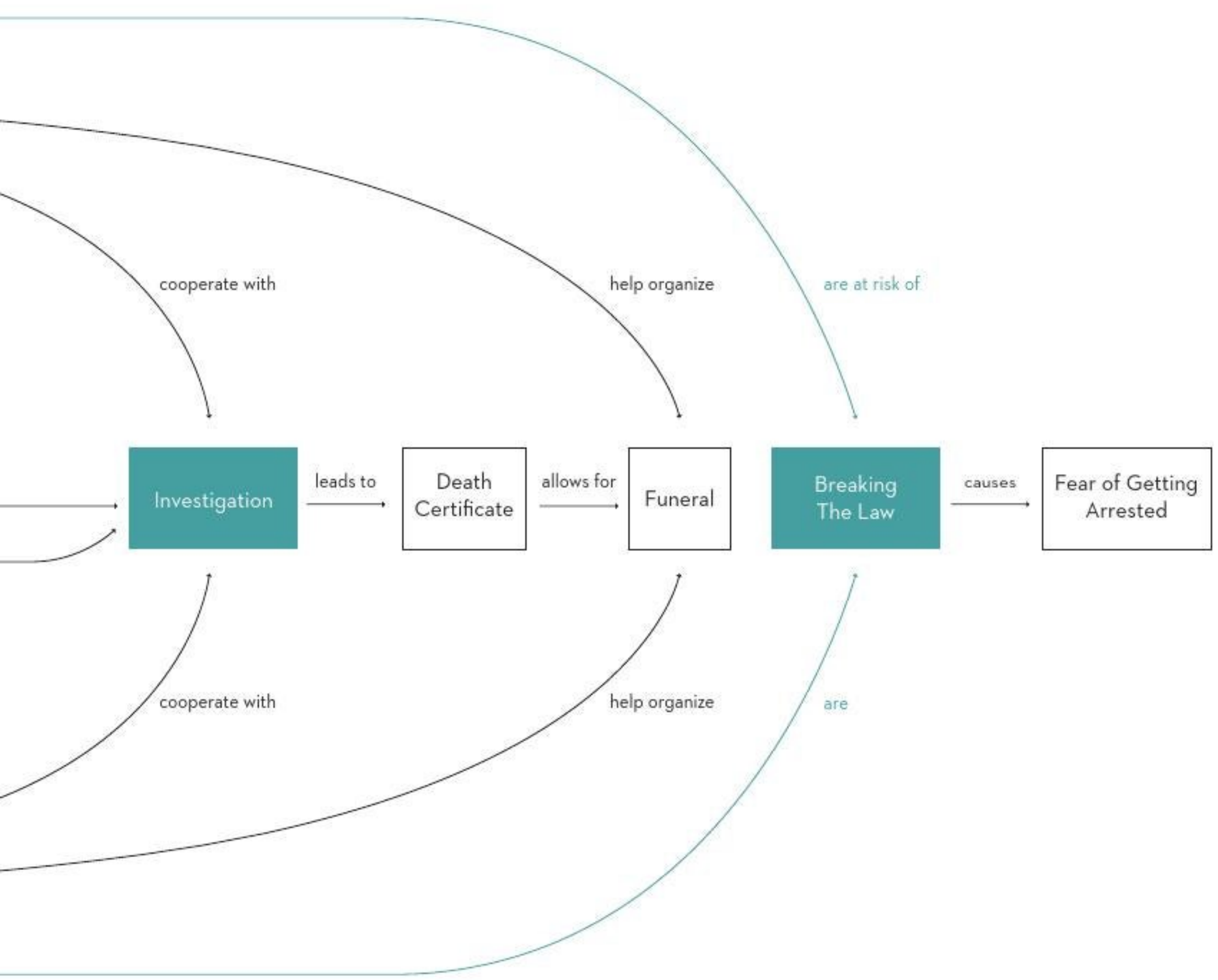
11 Paul Rubin, "Final Exit Network 'Assisted Suicide' Defendant Pleads Guilty Today to Endangerment," Phoenix New Times, June 30, 2011.

You can purchase a helium tank from Party City for about $50, then hook it up to an "exit bag," a plastic bag tightening by the neck. You gently put a bag over your head, fasten the bag to your neck and inhale helium gas. It is said that within a few minutes you will be unconscious, and death will occur in five to fifteen minutes. Details about how to use an exit bag and helium tanks are available in Final Exit. The helium method is a fast, effective, and economical option if you cannot obtain barbiturate drugs. Before you actually carry out the act, it is strongly recommended for individuals to write a suicide letter to let the authorities know that it was your decision to end your life. This way you can protect your family members and friends from getting into trouble. The last thing is to make sure to have a discovery plan. Someone has to discover your body and report the death to the right authorities. Some states require the person who "finds" your body to call 911, and in some other states, the person can call your doctors to sign a death certificate.

These are very simplified steps to secretly go through with self-deliverance. It is a lot like theater in that it is a carefully planned plot that an individual and his/her supporters have to act out. At the end, no one involved should talk about the fact they helped someone achieve self-deliverance. The act must be a suicide in the eyes of the law.

Illegal Process Diagram

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Medical Provider's Perspectives

A Medscape survey done in 2014 found that 54 percent of medical doctors favor physician-assisted dying, an increase from 46 percent in 2010.[12] Anecdotally, we also know that many physicians who support the end-of-life option are reluctant to declare so publicly for fear of repercussions in their workplace or medical community. The American Medical Association opposes aid-in-dying laws. However, not only does the AMA represent a declining number of physicians (only about one in three doctors are AMA members), 77 percent of physicians believe the AMA no longer reflects their views according to a 2011 survey of physicians conducted by Jackson & Coker.[13] In 2015, the California chapter of the AMA changed its position on physician-assisted dying from opposed to neutral, stating that they "believe it is up to the individual physician and their patient to decide voluntarily whether the End of Life Option Act is something in which they want to engage."[14]

Doctors

In an interview with Dr. Kenneth Prager, MD—professor of Clinical Medicine, director of Clinical Ethics, and chairman of the Medical Ethics Committee at Columbia University Medical Center—he expressed his personal opinion on the matter of physician-enabled suicide. He is against legalizing assisted suicide because he believes that from a doctor's perspective there is a difference between removing life support and actively enabling death. In his opinion, it is okay to pull the plug but not okay to provide medications that can kill someone. "Once you remove the bar," Prager asserted, "it cheapens the human life." He doesn't want more people to feel comfortable taking lives, and he'd rather attack the end-of-life problems via palliative care and morphine drip. He feels that there is so much more we can do in the medical field to provide palliative care. He maintains that the problem lies in the lack of medical education and that we need to teach doctors appropriate and effective ways to communicate the end-of-life issues to patients and family members.

I heard the same comment from Michael Zhu, a second-year medical student at the University of Texas. He is also not in favor of assisted suicide, pointing out that students learn how to treat patients and prolong their lives in medical school; they don't really have a course or program that teaches you what actually happens when someone dies or familiarizes you with the process of dying. In his opinion, general doctors are not trained to support the process of dying or to communicate the truth about approaching death to their patients. Another interesting thing I learned about from the conversation I had with Michael Zhu is the philosophy of medicine. The fundamental ethics of Western medicine date back to ancient Greece. Doctors are supposed to operate under the principle "First, do no harm." Young doctors need to sign this oath and swear to uphold it. In the medical field, it is equivalent to swearing on a holy bible in court. In that light, assisted suicide goes against everything the Western medical philosophy stands for. Atul Gawande, an American surgeon, writer, and public health researcher, briefly talked about the hardest challenges of his profession in his book Being Mortal. He illustrates

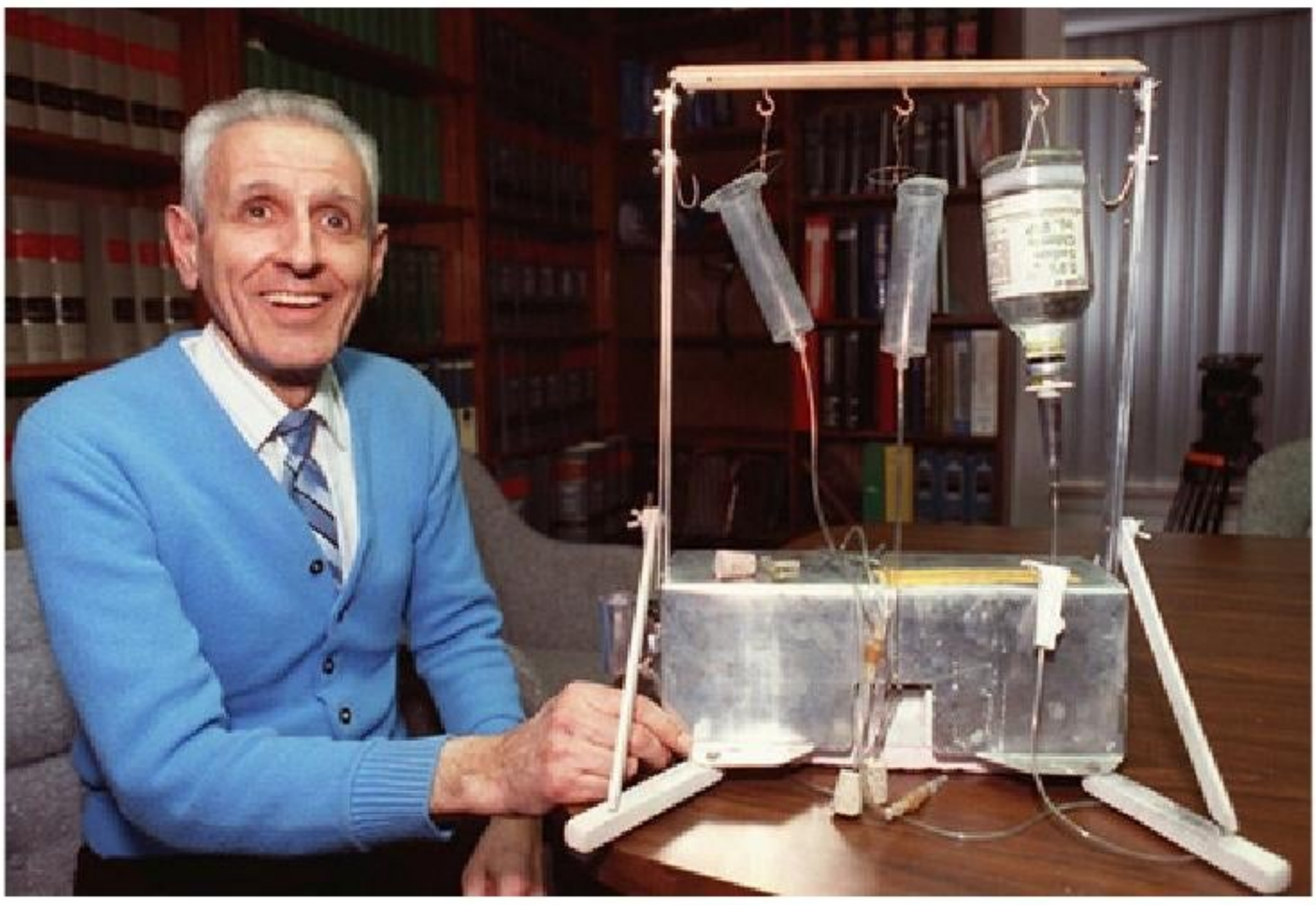
12 Leslie Kane, "Medscape Ethics Report 2014, Part 1: Life, Death, and Pain." Medscape, December 16, 2014.

13 "Survey: Physician Opinions of the American Medical Association," Jackson & Coker Industry Report, September 2011.

14 "CMA Changes Stance on Physician Aid in Dying, Takes Neutral Position on End of Life Option Act," California Medical Association, June 2, 2015.

“Certainly, suffering at the end of life is sometimes unavoidable and unbearable, and helping people end their misery may be necessary.”

— Atul Gawande, MD, MPH, Writer



Dr. Jack Kevorkian with his "suicide machine" in Michigan, AP photo

the modern experience of mortality and how to accept the limits of what medicine can do using his father's and his patients' stories. Ultimately, he said he supports physician-prescribed suicide because it can provide people control if they need it at the end.[15]

Dr. Jack Kevorkian

One medical professional who spoke up in support of assisted suicide was Dr. Jack Kevorkian (1928–2011). A Michigan pathologist who came to be known as Dr. Death, Dr. Jack Kevorkian claimed to have helped at least 130 patients who were suffering from illness end their lives.[16] He believed in providing patients with a peaceful way out and pushed the limit of Michigan law on assisted suicide during the '90s. The state tried to stop Dr. Kevorkian and eventually outlawed assisted suicide in 1993, but Dr. Kevorkian continued helping people in need and tested the law almost immediately. He was put on trial four times for assisted suicide but was declared innocent by the jurors. He videotaped his patients' wishes to end their lives; the footage was so compelling that the jurors couldn't find him guilty. Dr. Kevorkian developed his so-called suicide machine that allowed his patients to push a button to get a lethal injection flowing into their body. But then he tired of the argument of who should push the button and wanted instead to push the public opinion. He videotaped himself injecting the lethal drug into a man and played it on national television. He successfully got the nation's attention on the topic of assisted suicide, but this time, he was found guilty, convicted of second-degree murder, and sentenced to eight years in prison.

Dr. Kevorkian challenged social taboos about euthanasia and assisted suicide and pushed the public to think about end-of-life choices and law. Love him or hate him, he succeeded in making the taboo topic public and used media power to reach as many people as one man possibly could. Even though some doctors are supportive of physician-prescribed suicide and willing to write prescriptions for his/her patients, not all of those doctors choose to be present at the time of death for their patients. It seems to me that there is an emotional distance between just writing lethal prescriptions and being at the bedside of patients when they ingest the medications. Some doctors may not want to publicly declare the fact that they are in support of the issue because they could lose their jobs or become isolated from the medical community. In that sense, Dr. Kevorkian was a fearless and extremely compassionate doctor. He was not scared to stand by his convictions no matter what anyone thought. But within the community of people who support assisted suicide, the name Kevorkian is still a very controversial one. While some praise him for single handedly pushing the agenda forward, others feel that he was just a crazy man who tainted the image of the Death with Dignity movement. That said, Dr. Kevorkian never left the bedside of his patients. He was always there for them until they took their last breath, ensuring that all went well and providing mental support. He died at the age of eighty-three in a hospital in Michigan in 2011. His courageous work lives on among people who support death with dignity. Without him, many people would never have been exposed to the idea of assisted suicide.

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15 Atul Gawande, Being Mortal: Illness, Medicine and What Matters in the End (New York: Metropolitan Books, 2014), 245.

16 Clyde Haberman, "Stigma Around Physician-Assisted Dying Lingers," The New York Times, March 22, 2015.

Nurses

Another side of the story that I wanted to explore was the role of nurses in this movement. Doctors are extremely important in this issue because they are the gatekeepers for accessing lethal medications like barbiturates, but nurses play a huge part in end-of-life care and choices.

During an interview with Barbara Glickstein, a public health nurse and health journalist, she told me that I would be surprised to find out how many moral dilemmas nurses live with every single day. I was puzzled when she said that, and I did not know what to expect. According to her, there are institutional obstacles that nurses have to navigate through in their daily practices. For example, if a doctor tells family members that there is only a 2% chance of another treatment being successful, then the family members often cling to that slim chance. Because the doctor says there is hope, they truly believe that they will be part of that lucky 2% even though 98% of the time nothing will work. The typical scenario is that the family members end up pursuing the treatment even if the primary nurse knows that the patient is going to die regardless of any additional measures taken.

Sometimes, more treatment can actually kill patients faster than doing nothing and can bring more pain and suffering at the end.

The problem is that the nurses are not often in a position to offer the doctor their opinion or inform the patients about the reality of their condition. Nurses spend the most time with patients. They observe, monitor, and take care of a multitude of technical things, all while providing emotional support, yet their opinions are often completely ignored. Nurses generally do not want to be the ones who challenge the doctors. If they speak up, they may be seen as aggressive and disagreeable. There is definitely a communication issue between doctors and nurses, especially in regards to end-of-life medical care.

I spoke with Lisa Frans, a film producer who worked closely with Glickstein. Together they produced a documentary called American Nurse Project. After completing the film, they realized that there was much that we as a society haven't really explored—like the dying process. And so they began work on a new film titled Dying in America, the goal of which is not to tell people what to do but to actually present different options and talk about death and dying.

I asked Barbara Glickstein how the end-of-life options related to social inequality. Her answer was that health disparity is everywhere, but patients from working-class immigrant families actually fare better at the end of their lives than the average American because they are cared for by their family members. Dominicans in New York City, for example, tend to have large households with many generations living under the same roof, so kids grow up taking care of their elderly family members, a practice that is part of the Dominican culture.

Throughout her career as a registered nurse and health journalist, Glickstein came to the conclusion that "the farther we live from our family, the farther we are from death and dying." She said that often times, family members who live far away have a harder time accepting death and dying. If family members are involved in the last period of life, they are more comforted and the grieving process is easier. Her personal opinion on assisted suicide is that everyone should have the option to choose whether they want to end their lives with the help of physicians. She believes that doctors and nurses alone cannot bring about the cultural shift needed on this topic. We must also enact policy changes and educate healthcare providers to ensure that we have an end-of-life choice system that benefits everyone.

Non-supporters' Perspective

When I began my thesis research, I knew I needed to understand both sides of the argument on this topic. Even though I have my personal opinions, I wanted to talk to experts who are against the idea of legalizing assisted suicide. Margaret Dore is a lawyer and activist who asserts that assisted suicide should remain illegal. She argued that suicide is contagious, and often the media doesn't follow the suicide guidelines in reporting assisted-suicide cases. According to Recommendations for Reporting on Suicide©, the risk of additional suicides increases when the story explicitly describes the suicide method, uses dramatic graphic headlines or images, and repeats extensive coverage sensationalizing or glamorizing death.[17] Dore talked extensively about the case of Brittany Lauren Maynard, an American woman with terminal brain cancer who decided that she would end her own life when the time was right.

Brittany Lauren Maynard was only twenty-nine years old when she moved to Oregon from Alamo, California, so that she could take advantage of the state's Death with Dignity Act. She eventually became an advocate for the legalization of aid in dying and launched an online video campaign with Compassion & Choice. She said that her decision to take part in the campaign was not an easy one to make, but she chose to share her story because she felt that many people in our society and culture misunderstood the death-with-dignity issue. Her video was released on the morning of October 6, 2014, on People.com, and the reaction from the audience was beyond what she had imagined. More than 400,000 people went to her website, shared her stories, and donated to The Brittany Maynard Fund by that afternoon.[18] Brittany Lauren Maynard suddenly became the face of the Aid-in-Dying movement and her story was all over the Internet.

She had been diagnosed with progressive brain cancer in early January of 2014. She and her husband of just over a year, Dan Diaz, were trying for a family. But after the diagnosis, their lives revolved around hospital stays, doctor consultations, and medical research. Almost immediately after her initial diagnosis, she had a partial craniotomy and a partial resection of her temporal lobe. Both surgeries were an effort to stop the growth of her tumor. Unfortunately, in April, they learned that not only had Brittany's tumor come back, but it was more aggressive. Doctors gave her a terminal prognosis of six months or less to live. Because her tumor was becoming so large so quickly, doctors prescribed full brain radiation. The side effects were hair loss, first-degree burns on the scalp, and other symptoms associated with radiation treatment. Her quality of life would have decreased dramatically if not disappeared entirely. After months of research, they reached the heartbreaking conclusion that there was probably no treatment that could save Brittany's life, and the harsh side effects of the recommended treatments would have destroyed the time they had left. She said that she considered passing away in hospice care at her San Francisco Bay area home. But even with palliative medication, she could develop potentially morphine-resistant pain and suffer personality changes and the loss of

17 "Recommendations for Reporting on Suicide©," Reporting on Suicide.org.

18 Performed by Brittany Maynard, Dan Diaz, and Barbara Coombs Lee, "Brittany's Legacy: One Year Later," Compassion & Choices, October 5, 2015.

Brittany Maynard with her dog, Charlie, AP photo

“Having this choice at the end of my life has become incredibly important. It has given me a sense of peace during a time that otherwise would be dominated by fear, uncertainty, and pain.”

— Brittany Lauren Maynard

verbal, cognitive, and motor abilities of virtually any kind. The reality was that her body was young and healthy except for her brain, so she was very likely to hang on for a long time even though cancer was eating her mind like a monster. Even with the most amazing palliative care plans, she probably would have suffered to some degree in hospice care for weeks or even months. That would have been terrible for Brittany, of course, but her family would have suffered too, watching helplessly as she slowly and painfully drifted away.

She knew she did not want that kind of ending for herself or, more important, for her family. So she started researching alternative options and came across the Death with Dignity Act. That option would enable her to receive medical aid in dying. She could request a prescription from a physician for medication that she could self-ingest to hasten her dying process if it became unbearable. She decided that was the best option for her and her family. First they had to relocate from California to Oregon. She met the criteria for receiving aid-in-dying medication, but they had to establish residency in the state of Oregon to make use of the law. That required a monumental number of changes. She had to find new physicians, find a new home and establish residency in Portland, obtain a new driver's license, update her voter registration, and enlist people to take care of her animals. Her husband had to take a leave of absence from his job. The vast majority of families who are going through similar situations do not have the flexibility, resources, or time to make all these changes.

She had her prescription filled and it was in her possession for weeks. She said that she experienced a tremendous sense of relief just by obtaining the medication. At last she had a choice; she could decide to take it or not, and she was allowed to change her mind at any time. It seemed that having a choice and some control over the end of her life had become incredibly important to her, and having the prescription in hand gave her a sense of peace during a difficult time that could have been dominated by fear, uncertainty, and pain. With the Death with Dignity Act, she was able to move forward with her remaining days to seek joy and spend time doing what she loved to do: travel and see the wonders of nature with her family. The law became her safety net. Brittany was very clear about her stance on this matter. She said,

"I would not tell anyone else that he or she should choose death with dignity."

And she posed the question of who had the right to tell someone that he or she didn't deserve this choice, that some deserve to suffer for weeks or months at the end of their lives, experiencing tremendous amounts of physical, emotional, and possibly even financial pain. Before Brittany's video campaign, there were aid-in-dying bills in four states. Soon after her message became popular online, many states introduced aid-in-dying bills. The president of Compassion & Choices, Barbara Coombs Lee, said that it was her message that boosted the organization's capabilities to the maximum. Today, Brittany's husband works full time as a spokesperson for Compassion & Choices, carrying on Brittany's mission to make sure that people in every state have humane end-of-life choices available to them. Brittany didn't live long enough to see her home state, California, pass the

End of Life Option Act. But come June 9, 2016, her fellow Californians will have the legal right to end their suffering with dignity.[19]

Margaret Dore also told me about Jeannette Hall, an elderly woman who chose to die then survived. A resident of Oregon, she voted in favor of the Death with Dignity Act in 1994. Six years later, she was diagnosed with inoperable colon cancer. She was fifty-five years old at the time, and her doctors gave her two options: She could get radiation and chemotherapy and try to fight the cancer, or she could take a lethal dose of barbiturates to end her life. Scared of what the radiation and chemotherapy would do to her, she chose what she thought would be the easy way out, to use the Death with Dignity Act. She was considered terminal because she refused treatments. Then she met Dr. Kenneth Stevens at the Oregon Health and Sciences University specializing in radiation medicine. He refused to prescribe her the medication, hoping that he could change her mind. Dr. Stevens is opposed to assisted suicide because he believes that he is in medicine to heal people, not to kill them. Eventually, he learned that Hall had a son who was training to be a state trooper. Her son didn't even know about her condition much less her decision to end her life. So Dr. Stevens urged Hall to reconsider her decision for her son's sake. Fifteen years later, Hall celebrated her seventieth birthday with her son.[20] Dore argues that how long a person has left to live is simply a doctor's prediction and it is not always reliable.

As a result, people can end their lives prematurely, choosing a way out that makes life seem less valuable. In my opinion, that is why it is important to make sure that applicants have two physicians agree on the diagnosis and that other safety precautions are in place. If those conditions have been met and the patient then decides that they truly want to die rather than going through with treatments, I think it is their right to make that choice.

Dore also brought up the fact that the decision to end one's life may not always be so cut and dry. People have been known to persuade their elderly family members to die early so that they can cash out their lucrative life insurance policies and/or simply save money by not getting treatment. She mentioned the case of Victorino Noval, a seventy-eight-year-old multimillionaire who lived in California. He entered a Kaiser hospital in Southern California on April 28, 2010, with a diagnosis of aspiration pneumonia. He was intubated, placed on a mechanical ventilator, and sedated. His medical history included early stages of Parkinson's. Apparently, Noval was totally independent prior to his hospitalization.

He lived in his own home, drove his own car, performed his own daily living activities, managed his own finances and investments, and had an annual income of $3 million. He was worth an estimated $60 million at the time of his death.[21] On May 7, 2010, he died from terminal extubation. Later on, his son, Hector Nobel, sued the hospital for removing the life support. He accused his sisters of persuading his father to go through with extubation, and he claimed that his

19 Patrick McGreevy, "Aid-in-dying Law to Take Effect June 9 in California," Los Angeles Times, March 10, 2016.

20 Kelsey Harkness, "SOCIETYNEWS Assisted Suicide: How One Woman Chose to Die, Then Survived," The Daily Signal, May 18, 2015

21 William Dotinga, "Grim Complaint Against Kaiser Hospital," Court House News Service, February 6, 2012.

sisters convinced the hospital staff that he was a drug addict and suffered from mental illness.

Margaret Dore also argued that the handling of death certificates in these cases is dishonest. In the states where assisted suicide is legal, when patients choose to end their lives, their death certificate says "death by natural causes" and there is no mention of assisted suicide. I hadn't really thought about that until she mentioned it to me, but my immediate reaction was that there's no benefit to listing the cause of death as assisted suicide. We know if someone dies with physician-prescribed medications because the legal process requires them to report it, so the cause-of-death statistics wouldn't be affected. Also, while many may believe that there isn't much difference between someone who is depressed and commits suicide and someone with a terminal illness who chooses assisted suicide, the law must make the distinction. I believe the reason it is not recommended to write "death by assisted suicide" on death certificates is that any mention of suicide denies access to life insurance. In the cases where patients were already dying from fatal diseases, the intention to end life is different from suicides committed by otherwise physically healthy people. To deny life insurance to a patient's loved ones for taking a measure of control over a death that was inevitable doesn't make sense.

I have spoken to Diane Coleman, the president of NotDeadYet.org. She is opposed to the aid-in-dying movement because she believes "disability" is the issue in legalizing assisted suicide. Intractable pain has been emphasized as the primary reason for enacting assisted suicide laws, but the top five reasons Oregon doctors actually report for issuing lethal prescriptions are related to disability issues. According to the Oregon Death with Dignity Act Annual Report, the three most frequently mentioned end-of-life concerns were: loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (86.7%), and loss of dignity (71.4%). Coleman believes that those are solvable disability issues. She maintains that we need to put more effort into treating those disability-related issues first. While I agree that those are disability-related issues, near the end of life, people slowly become disabled one way or the other. They are often in pain both physically and emotionally, and sometimes there is not much doctors can do about the unavoidable suffering and eventual death.

There are some instances where I think assisted suicide would be uncalled for. If you have newly injured your spinal cord, for example, and become paralyzed from the waist down, I don't think you should give up on life. But if you are really having trouble living your life with disabilities and are suffering, who can say you shouldn't end your life? I think pain and suffering in some ways is subjective and must be considered when deciding what dying with dignity means to you. In the film, The Sea Inside, the main character, played by Javier Bardem, advocated for euthanasia and the right to end his life. The film is based on the true-life story of Ramón Sampedro, who in 1968 became a quadriplegic after a diving accident at the age of twenty-five. He was paralyzed from the neck down, and for the next twenty-eight years he fought for the right to die with dignity until his death in 1998 from potassium cyanide poisoning. A few days later, his close friend, Ramona Maneiro Castro, was arrested for assisting his suicide. Maneiro was released due to lack of evidence, and no further charges were ever filed in connection with Sampedro's death.[22] He really wanted to die because he felt his life was not worth living, though he couldn't kill himself since he was only able to move his mouth. He managed to commit suicide after nearly three decades of searching for someone who would help him do small tasks that would enable him to drink the potassium cyanide. It is a difficult thing to say whether Sampedro deserved a choice to end his life. His condition was not terminal, yet his quality of life made living unbearable. His case really challenged our preconceptions about assisted suicide and euthanasia.

22 "A Suicide Tape on TV Inflames the Issue in Spain," The New York Times, March 9, 1998.

“The person who really loves me will be the one who helps me die.”

— Ramón Sampedro

The Last Destination

In Europe, assisted suicide has been legal in Luxembourg since 2009 and both the Netherlands and Belgium since 2002. In Switzerland, ending your life with the help of physician-prescribed medications has been legal since 1942. There are no regulations on people who choose assisted suicide in Switzerland; they don't even have to be Swiss citizens. As a result, more and more people who seek a peaceful way to die visit Switzerland as their last destination. There are six right-to-die organizations that assist people in Switzerland. Approximately one-third of assisted suicides are tourists mainly coming from Germany, the UK, and France. For those suicide tourists, Dignitas is the last organization that they have a relationship with.

Dignitas is a Swiss nonprofit group that helps those with terminal illnesses or severe physical and mental illnesses to die. They have certified doctors and nurses who help patients achieve a peaceful, dignified death. Ludwig A. Minelli, a Swiss lawyer, founded Dignitas in 1998. The group has helped more than a thousand people die in Zürich to date. Among the many right-to-die groups in Switzerland, Dignitas is considered one of the most controversial. In the documentary Terry Pratchett: Choosing to Die, a 2011 television documentary produced by KEO North for BBC Scotland, directed and produced by Charlie Russell, author Terry Pratchett (1948–2015) visits Dignitas and witnesses the death of Peter Smedley, a seventy-one-year-old English millionaire hotelier with motor neuron disease. The film captures the last moments of Smedley's life with no editing, revealing the sounds and imagery of death by lethal medications.

After watching the death of Peter Smedley, I realized dying is not quiet or visually pleasant even when it is a chosen death with lethal drugs. It probably will never be silent and entirely beautiful no matter how much we want it to be. Dying is a messy and unpleasant thing, which we all have to acknowledge. An Interesting thing I learned from this film is that the locations in which suicide tourists end their lives are restricted to Dignitas houses or apartments situated in an industrial part of outer Zürich because of the governmental regulations. In a PBS FRONTLINE documentary The Suicide Tourist, Craig Colby Ewert (1947–2006), a Chicago native and retired university professor in Northern England diagnosed with Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, ended his life in an apartment rented by Dignitas.

Looking at the experiences of people who chose to die with the help of Dignitas from the lens of design, there are many touch points throughout a patient's journey. Doctors carefully interact with patients and their family members. There seems to be a standard script that members of Dignitas follow. Dignitas members who shepherd patients through the process make sure to explain what is happening to the family members while the patient is dying. Those small actions seem to ease the experience of loved ones who are present at the moment of chosen death. Dignitas also offers funeral services, cremation, and the packaging and shipping of the ashes back to the family members. Personally, I think Dignitas's thoughtful service offerings are inspiring. It takes the burden off the family members and makes the difficult experience a little more soothing and less complicated.

The assisted suicide clinic, Dignitas house in Pfaeffikon near Zurich.

The room at the Dignitas house, near Zurich, in which people end their lives.

“Whether or not this practice is legalized, seriously ill patients are asking us to talk about it, they’re asking us to consider it seriously.”

— Timothy E. Quill, M.D.

Vulnerable Groups

Some people fear that once we legalize assisted suicide we would put society's most vulnerable groups of people at risk. I wondered about similar questions throughout my research. For instance, would the poor be more likely to seek assisted suicide because of financial reasons? After speaking to Margaret Pabst Battin, professor of philosophy and medical ethics at the University of Utah, I learned that according to research she and her colleagues have conducted, there is no evidence of heightened risk in physician-assisted dying in Oregon and the Netherlands for vulnerable groups, except for people with AIDS.[23] In the study, the vulnerable groups included the elderly, women, the uninsured, people with minimal educational, the poor, the physically disabled or chronically ill, people with psychiatric illnesses, and racial and ethnic minorities. Their conclusion was that in places where assisted dying is already legal (Oregon and the Netherlands), there is no evidence suggesting that physician-assisted suicide will have a disproportionate impact on patients despite the data showing a heightened risk for patients with AIDS.[24]

I wondered why patients with AIDS are more likely to use assisted dying than any other vulnerable groups. What are the reasons that people with AIDS or HIV consider physician-assisted dying? In a qualitative study conducted by Canadian researchers, they learned that patients with AIDS or HIV-1 desire euthanasia or physician-prescribed suicide because of disintegration and loss of community, which combines to create a feeling of loss of self.[25] For those patients, the progress of the HIV-1-related disease is accompanied by loss of physical functions, and possibly mental functions, which creates dependency on others such as caregivers and the feeling of disintegration. They also lose the desire and opportunity to maintain social relationships because of their health condition. They feel isolated from society and tend to keep themselves isolated. In the end, their quality of life becomes so compromised, and control over their own bodies so limited, they feel they might as well be dolls. For them, euthanasia or assisted suicide is a way to prevent losing themselves physically and mentally. They don't want euthanasia or assisted suicide because of a desire to die, but rather as a means of avoiding becoming a doll with no self-control.

In an interview with a gay man who has been HIV positive for more than thirty years, he told me that he lives with a thought of dying everyday. He has seen many of his friends die horribly from AIDS, and as is true of many HIV patients, the idea that that could be his fate is never far from his mind. He said,

"We live with the thought every day,"

I asked him why he thinks that people with AIDS are one of the only vulnerable groups that showed heightened risk for using assisted dying. His answer was somewhat shocking but made complete sense to me.

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23 Margaret Pabst Battin, Agnes Van Der Heide, Linda Ganzini, Gerrit Van Der Wal, and Bregje D. Onwuteaka-Philipsen, "Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in 'Vulnerable' Groups," Journal of Medical Ethics Vol.33, no. 10 (2007): 591–97.

24 Ibid.

25 James V. Lavery, Joseph Boyle, Bernard M. Dickens, Heather Maclean, and Peter Singer, "Origins of the Desire for Euthanasia and Assisted Suicide in People with HIV-1 or AIDS: A Qualitative Study," The Lancet Vol.358 (August 4, 2001)

"Taking pills (drugs) is very familiar to us . . . like I know how to do this because I have done it many times," he said. He talked about the familiarity of using drugs among gay people. He has done many drugs in his life, but a big part of the reason he did them was to escape from reality and all the problems he had. The drugs gave him a temporary way out of situations that he had no control over, and many gay people have done the same. It seems that in the gay community, especially in the major West Coast urban areas, suicide using lethal drugs is a common and accepted practice; AIDS patients know how to get help in achieving peaceful death if that is what they desire.[26] There are other ways to end life—using a gun, jumping off the George Washington Bridge, hanging, or cutting one's wrist—but he said that those methods are too foreign to him, and he wouldn't know what to do. However, taking lethal medications is not something new and scary. He doesn't have any children, so there is nobody that can look after him when he gets sick. He is completely on his own, and he doesn't want to be a burden for other people. So if he is at the point in his life where he feels like there is no way out physically or mentally, he would choose a more familiar way to exit.

Animal and Human Euthanasia

As I was doing research, I couldn't help but make connections between human euthanasia and animal euthanasia. I wanted to know more about the process of animal euthanasia, so I called my dog's veterinarian, Jennifer Tsung, DVM, at Inwood Animal Clinic in upper Manhattan. She was surprised and a little confused as to why I was calling her.

But she explained to me that in animal euthanasia, she often uses a two-injections method. The first shot sedates the animal, and the second shot overdoses the animal and causes cardiac arrest very quickly. For the second shot, most veterinarians use barbiturates like pentobarbital. I asked her what she thinks about the relationship between human and animal euthanasia. She was kind of shocked about my question and answered, "These are two completely different things and you cannot compare." But why can't we compare the two? I wondered. Is it because we sort of "own" the animal, and they cannot express and decide what is best for them, so we can choose the painless death for them when their time comes? If it is considered ethical to put an animal to sleep when they are suffering from a condition that cannot be cured or treated, why is the same not true for human beings?

To further investigate this question, I reached out to Jessica Pierce, PhD. She is a bioethicist and writer who is working on a book focused on palliative care for animals and the ethics for keeping pets. She said that surprisingly there hasn't been more discussion around animal and human euthanasia. "I think it makes people nervous . . . as if comparing humans to animals is an insult." I sensed a similar feeling from the conversation I had with Dr. Tsung. You often hear from individuals involved in a situation where an animal has to be put down that euthanasia is the responsible thing to do, that it would be wrong to prolong the animal's suffering. People talk about it as if it would be doing the animal a favor by giving them a peaceful death. Trying to keep them alive with medical interventions can be seen as a selfish thing to do. But then, when it comes to humans, it is illegal and generally considered immoral to practice euthanasia on humans. I think

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26 Battin, Margaret Pabst, Ending Life: Ethics and the Way We Die (New York: Oxford University Press, 2005), 72.

the same logic and arguments for animal euthanasia should apply to humans as well. Why is prolonging the suffering of an animal wrong, while prolonging the suffering of a human accepted and practically required by law?

The discussion of human and animal euthanasia eventually led me to death penalty issues. Dr. Tsung told me that some animal drug companies refused to sell the drugs for human use because of capital punishment. Neuroscientist Elaine Zhang told me that the drug used to paralyze lab rats is called pancuronium bromide (one of three in the cocktail), and it is hard to obtain. In the neuroscience lab at Columbia University, they can't get a constant supply from the same supplier because the drug has been used in killing capital punishment inmates in some states, like Ohio and Kentucky. It seems that the flow of lethal drugs are controlled and regulated heavily, and at the core of it is the issue of the death penalty.

Futuring Workshop

I organized a futuring workshop with the family members of elderly and terminally ill people as a way to start conversations around death and dying. I asked them to imagine the way they want to die in the future then to create objects that they would have at the last moment of their lives. I created cards that would help them narrow down their death in a fictional future. The cards are separated into three categories-mood, location, and situation. The mood cards provide the feeling of their last moment—comfort, delight, relief, calm, pleasure, pride, amusement, guilt, anger, or satisfaction. The location cards provide an environment in which your death may take place—at home, hotel, nursing home, vehicle, beach, forest, park, museum, airplane, or church/temple. The situation cards provide a context in which the death may happen—you are dying alone, with someone, with two other people, surrounded by friends and family, and with someone's help.

Participants took one card from each category, and composed a suicide note by filling in the blanks on a pre-written template. Then four participants created their objects using various materials and a hot glue gun. At the end, we had four speculative objects with stories in which the objects may live.

DARK WONDER

Designing for the Last Moment Workshop

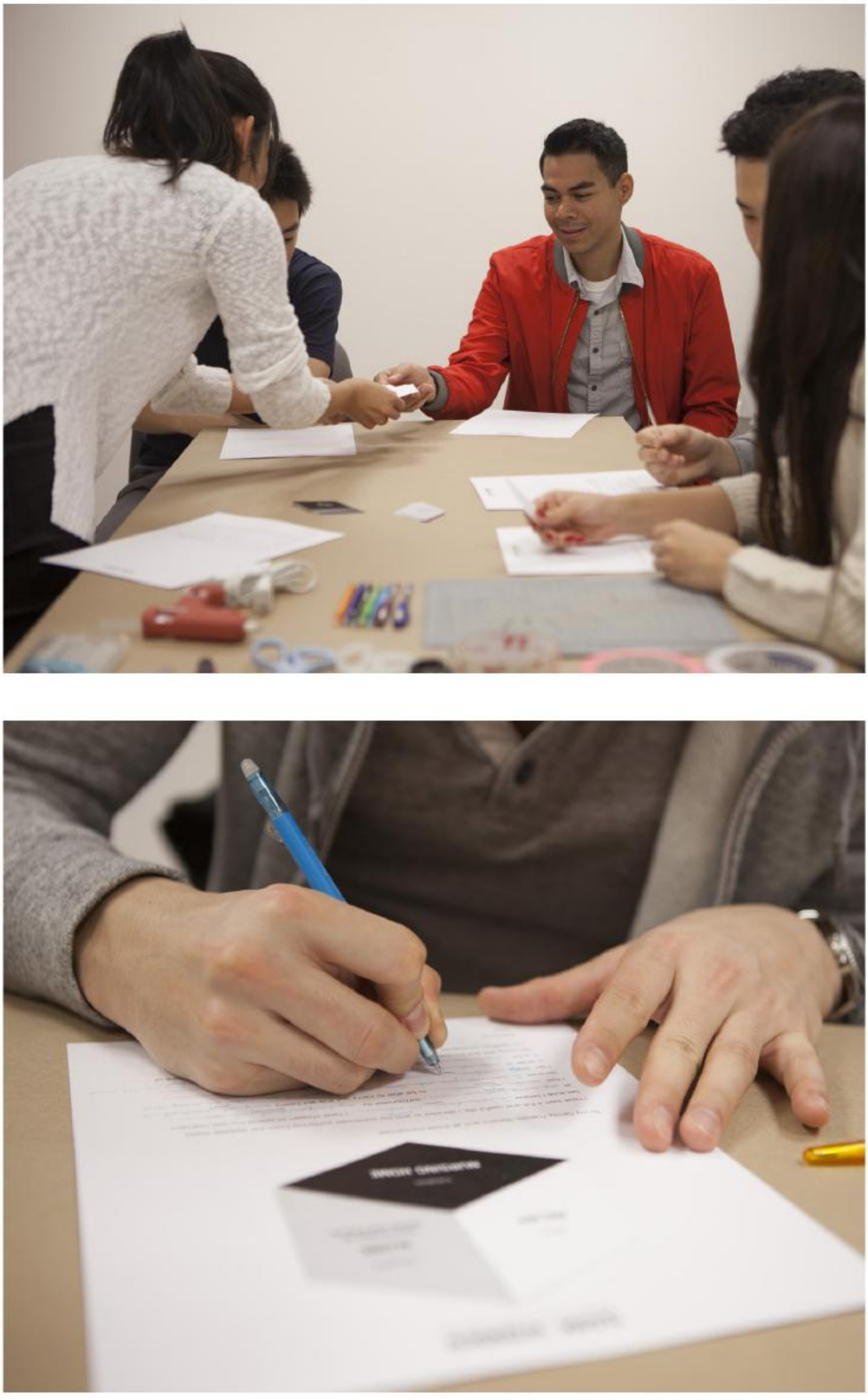
To my family, friends, doctors and all those concerned:

I have lived a full and useful life. I decided to end my continued suffering from the disease today because I believe . I have chosen to spend my last moment at , surrounded by I feel to be able to carry out this act (with) because I got from in order to It is for

My Living Will and Durable Power of Attorney for Health Care attached to this letter as evidence of my carefully considered wishes with regard to my death.

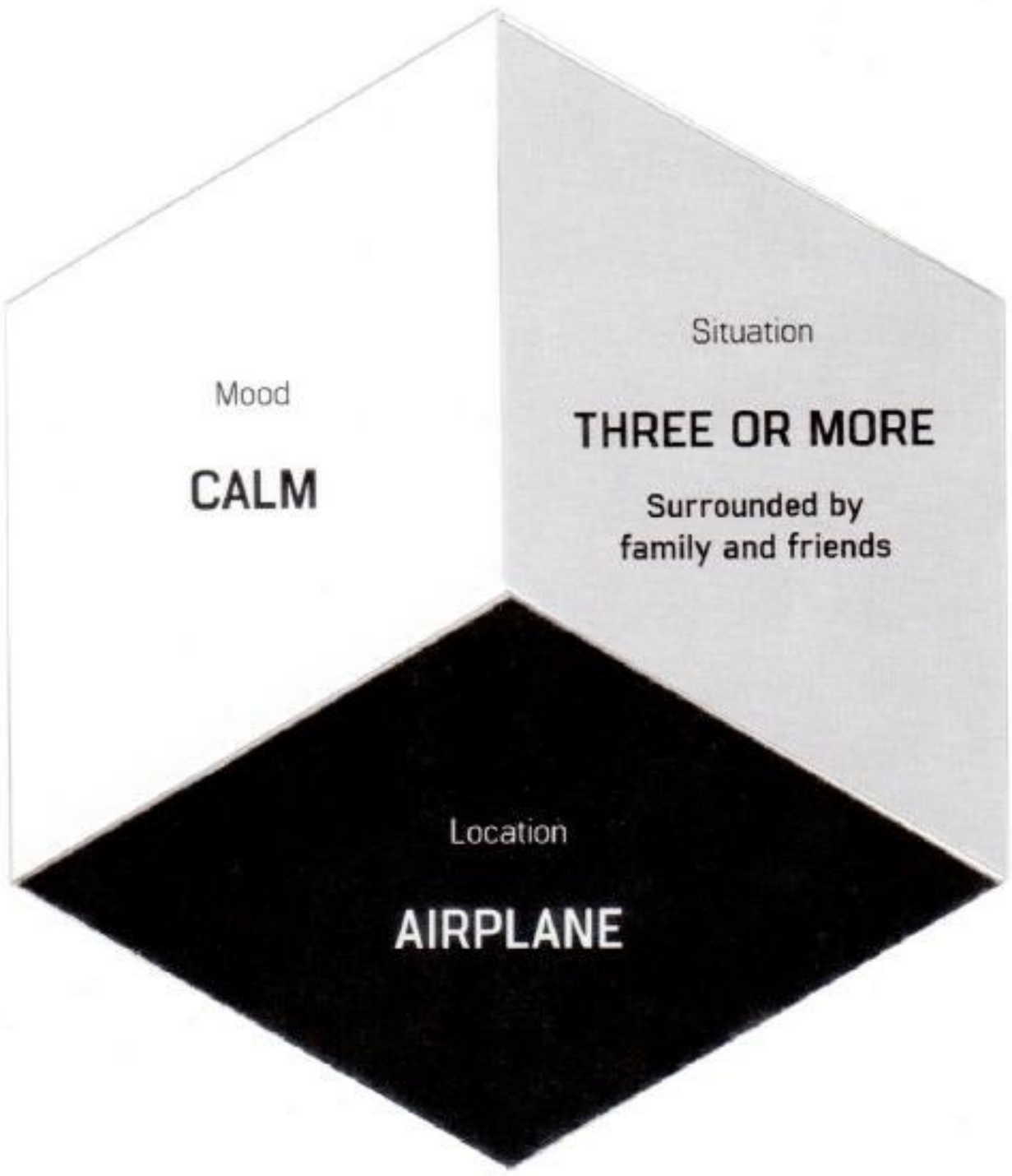
Signature:

Date:



DARK WONDER

Designing for the Last Moment Workshop



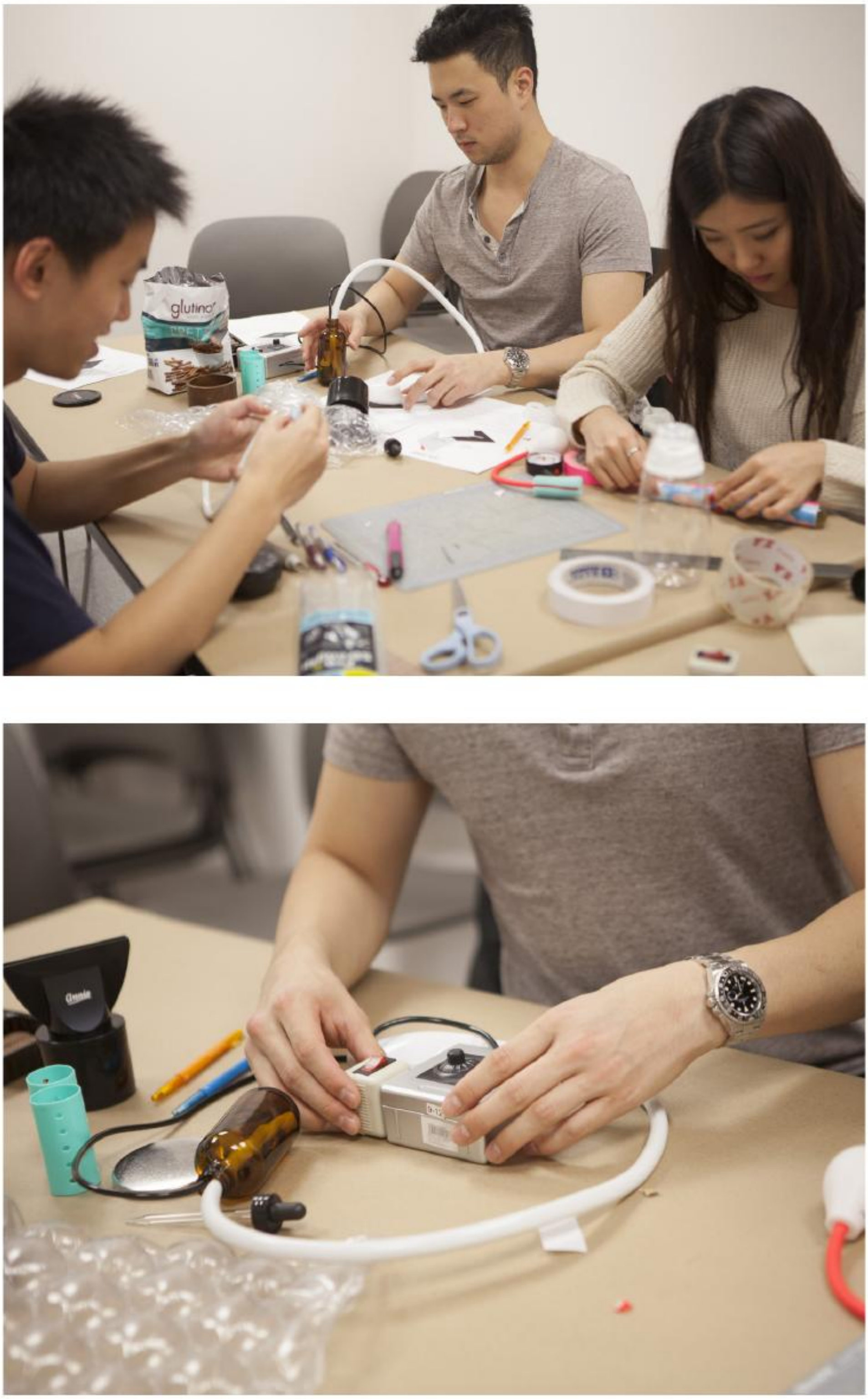
To my family, friends, doctors and all those concerned:

I have lived a full and useful life. I decided to end my continued suffering from the disease today because I believe humanity is doomed (opinion). I have chosen to spend my last moment at airplane/spacecraft (location), surrounded by outer space (environment). I feel calm (emotion) to be able to carry out this act (with) friends + family (people) because they are all I have left in the world (emotion). I got this seed bank (object) from Elon Musk (company / location / people) in order to feel like there is hope (intention / desire / need). It is for popluate life on Mars (usage / value).

My Living Will and Durable Power of Arttorney for Health Care attached to this letter as evidence of my carefully considered wishes with regard to my death.

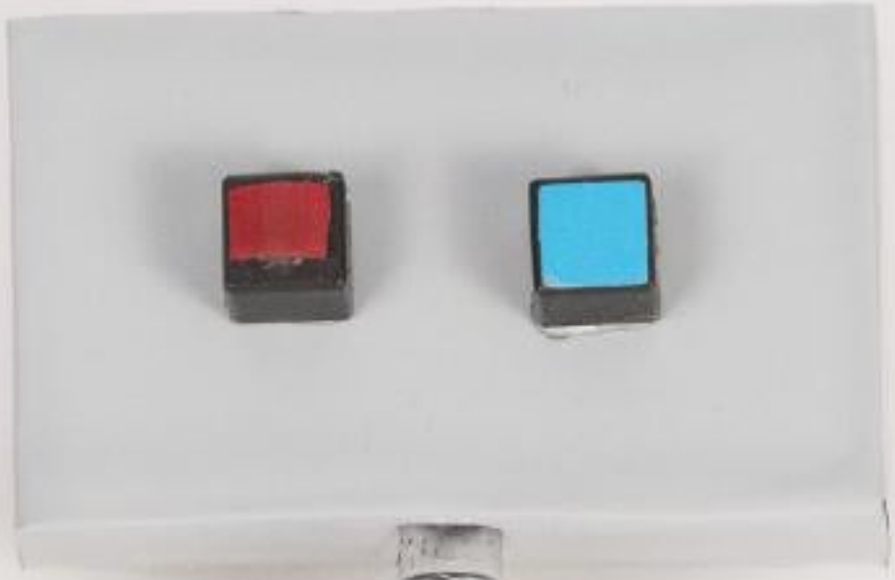
Signature:

Date: 03/25/2052



A connected memory device

It a device that connects to your loved one and projects memories that you have with that person in your head during the last moments of your life. It was made intentionally for couples to spend their final moments together. The participant wanted to remember the memories before her peaceful death. She chose the date to be May 29, 2115 because it would be her anniversary with her boyfriend.
By Judy Lee



A drug-dispensing machine

It is a portable device that allows users to combine drugs together to create a desired ending. The participant said since he gets to die completely alone in the museum, he wanted to do drugs that he always wanted to try. He wanted to be able to hallucinate and imagine a wall depicting his life.
By Anthony Olivence

A laughing gas machine

It is a portable machine that you could plug in anywhere you wanted. The participant wanted to smile during the last moments of his life because he felt that is the kind of attitude he wanted to have about death. This scenario was interesting because he chose the cards that situated his death in a nursing home, dying alone instead of surrounded by his friends and family, and other participants felt sorry for him. But he felt that he might as well make the best out of his circumstances and smile at the end.
By Paul Namkoong

A seed bank

It is an object containing seeds that could populate Mars. The participant's death was situated to be with more than two people surrounded by friends and family, so he thought his death should include a shared mission. The mission part was an interesting concept that neither I nor the other participants had ever thought of. It opened up the discussion about adding meaning to our deaths and made the act of dying more proactive rather than passive and negative.
By Calvin Szeto

What I learned from the workshop is that when people know that they have control over their deaths, it allows them to open up their minds and discuss how they want to die. The fact that it was set way off in the future made everything seem possible, and there was no judgment as to how they wanted to die. That freed the participants to evaluate what matters at the end and talk about death and dying without apprehension or fear. The most interesting thing I got out of this workshop was the conversation around death having a mission and purpose. If we can see death as more than just an end or an exit, what does it look like? What do we want to leave behind after our death? It can be anything from teaching your children about meaningful dying processes to influencing the law around assisted suicide. For Brittany Lauren Maynard, her death and choice meant making a significant contribution to the aid-in-dying movement. If we have time and choice to plan for our death, we may be able to think beyond what death and dying mean today.

Early Exploration

My early research into the issue of assisted suicide focused more on exploring commentary, visualizing reactions to the current landscape of aid in dying, or imagining what could happen if the world was different. These exercises served as idea generators and helped me to get out of my head and into the hands. Concepts are divided into three main categories—objects, apps, and services.

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DRIVERS LICENCE
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CLASS

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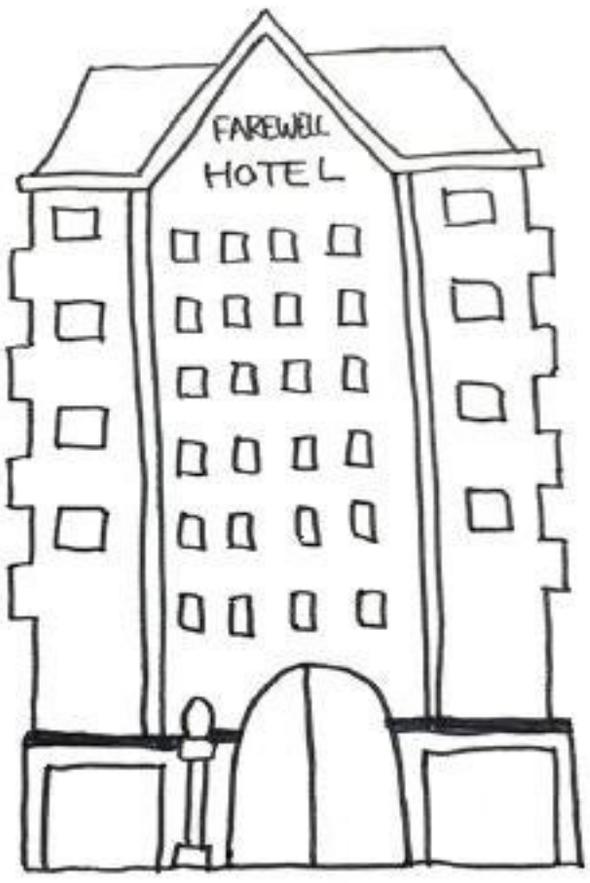
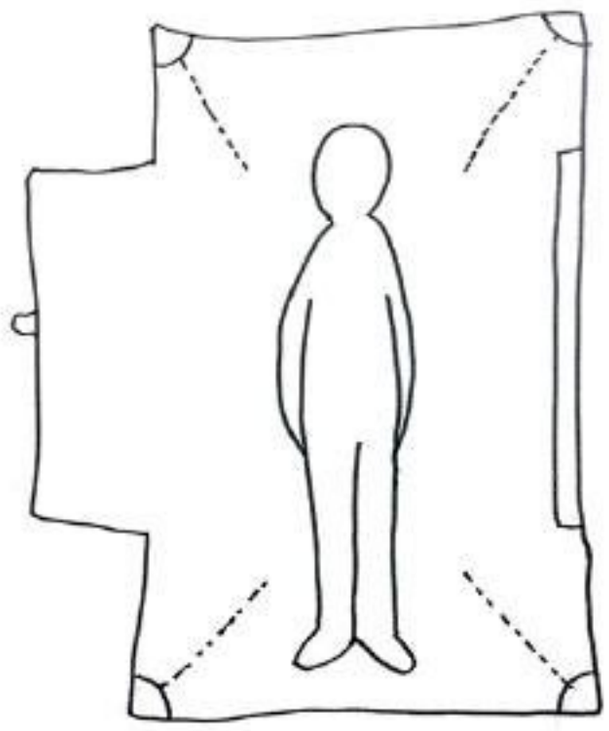
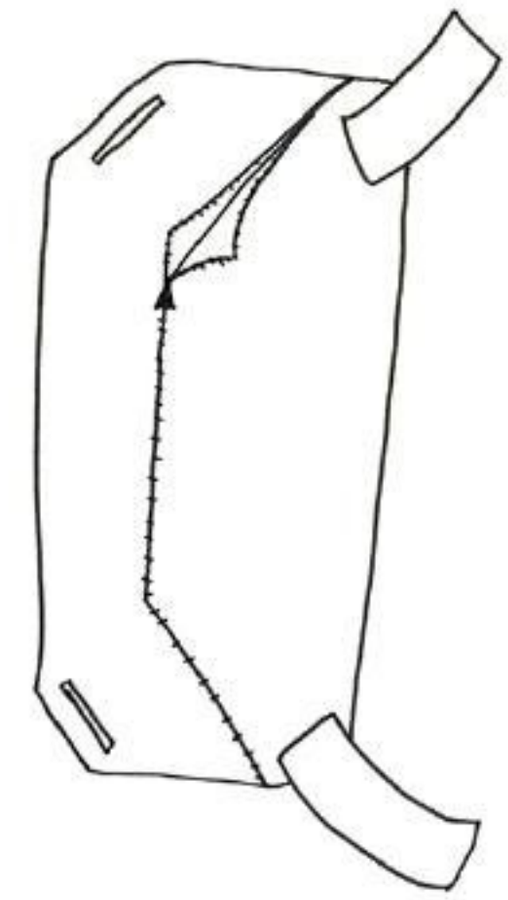
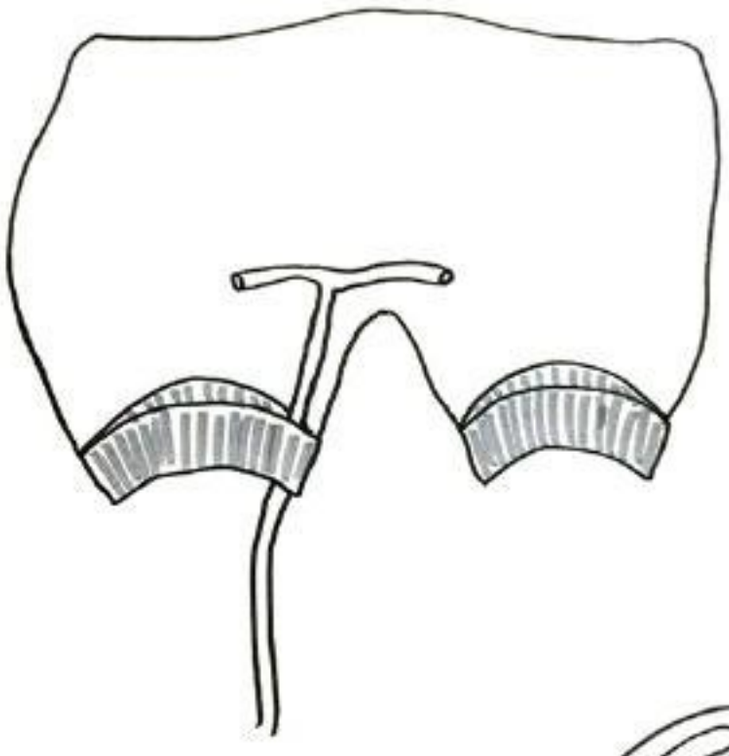
DAYS LEFT


FAREWELL
HOTEL



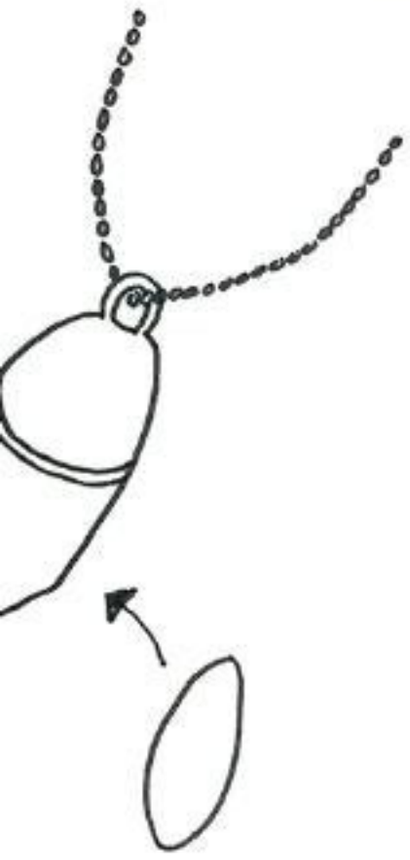


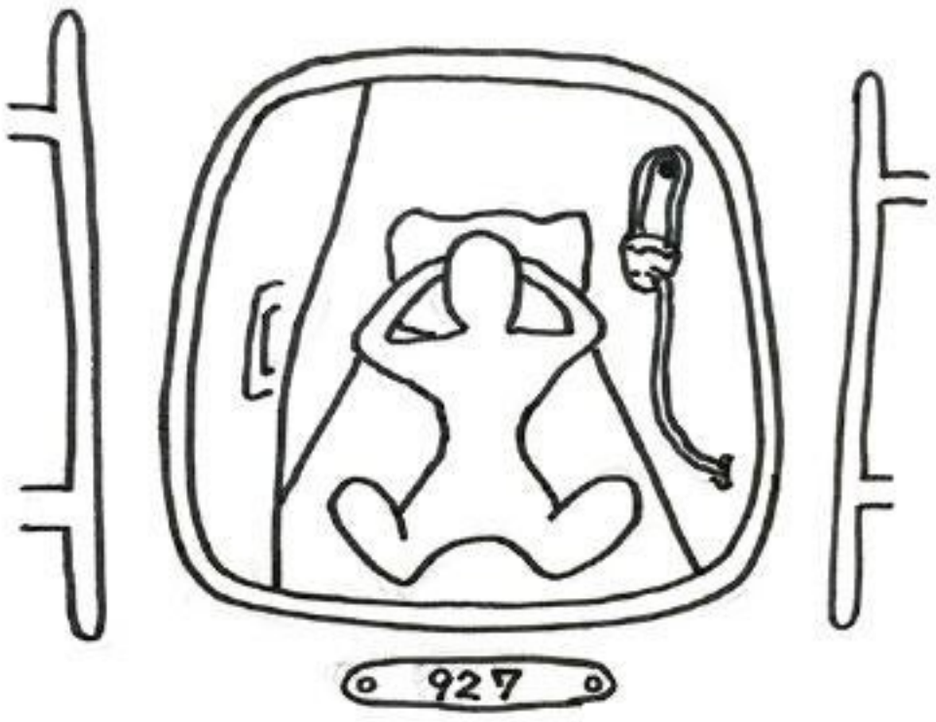


everything
You Need
WELCOME
FAREWELL

LAST AID KIT

Last Moment in Hawaii
FAREWELL in ROME

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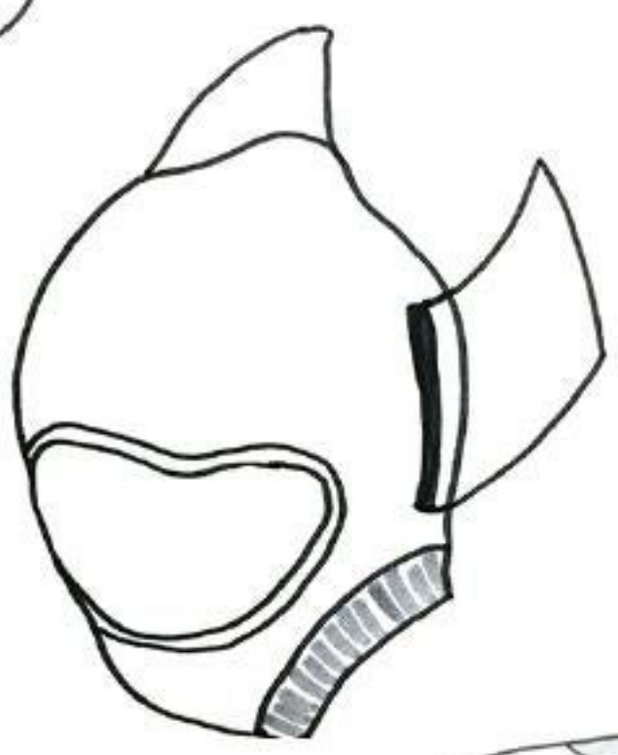
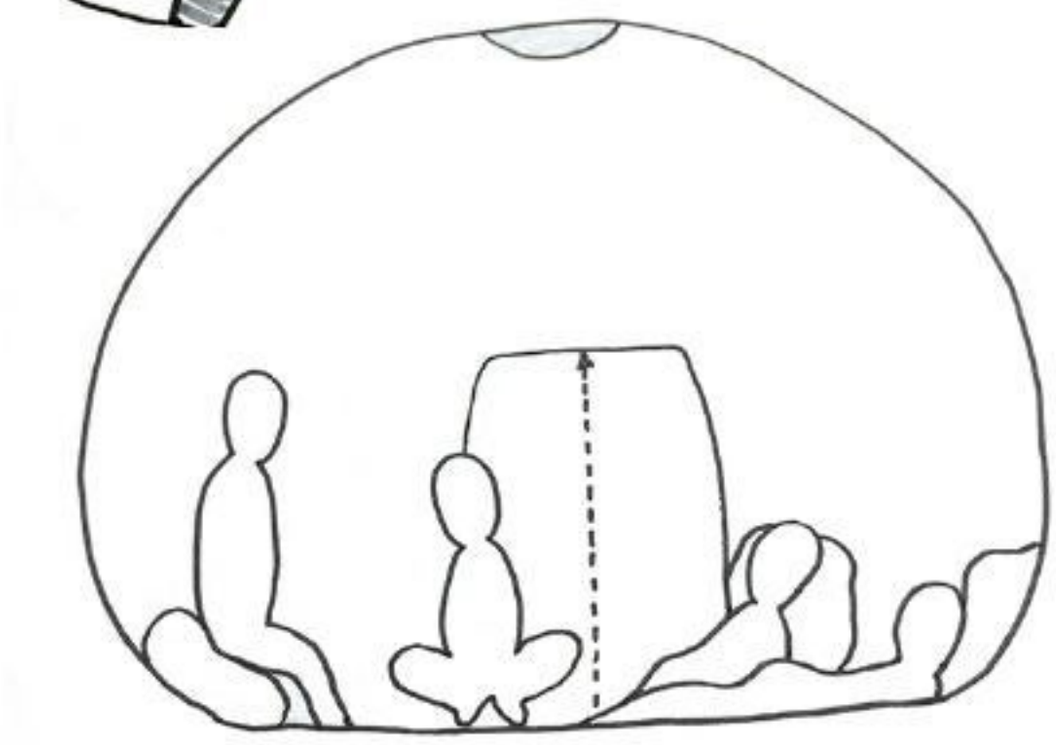




Death with Dignity ID

Very early on in my speculative work on the topic of assisted suicide, in a hypothetical world where death with dignity is fully legal and people have the option to choose dignified death, I imagined an emblem on your ID card that would indicate your desire not to be resuscitated in the event of an accident. The program would be integrated into an existing governmental identification system such as driver's licenses.

A do not resuscitate form (DNR) is a legal directive to withhold cardiopulmonary resuscitation (CPR) or advanced cardiac life support (ACLS) at the patient's request in case their heart stops or they stop breathing. Today, you need to have the form on you at all times in order to have your wish fulfilled. So if patients have a complication in a hospital and don't want to live with life support equipment, they have to have their living will and durable power of attorney for health care with them. To avoid the unwanted saving of lives, a simple emblem similar to the red heart (the organ donor symbol) can help patients to identify themselves as believing in dignified death. Some people choose aid in dying because they do not want to live dependant on life support, so they'd rather end their lives before they get to the stage in their illness that may require technological intervention.

NEW YORK STATE
DRIVER LICENSE
CLASS D
ID: 478 340 195
BLOOMBERG
MICHAEL,R
17 EAST 79 ST
NEW YORK NY 10075
02-14-42
EXPIRES: 02-28-15
ORGAN DONOR

Safe Distance

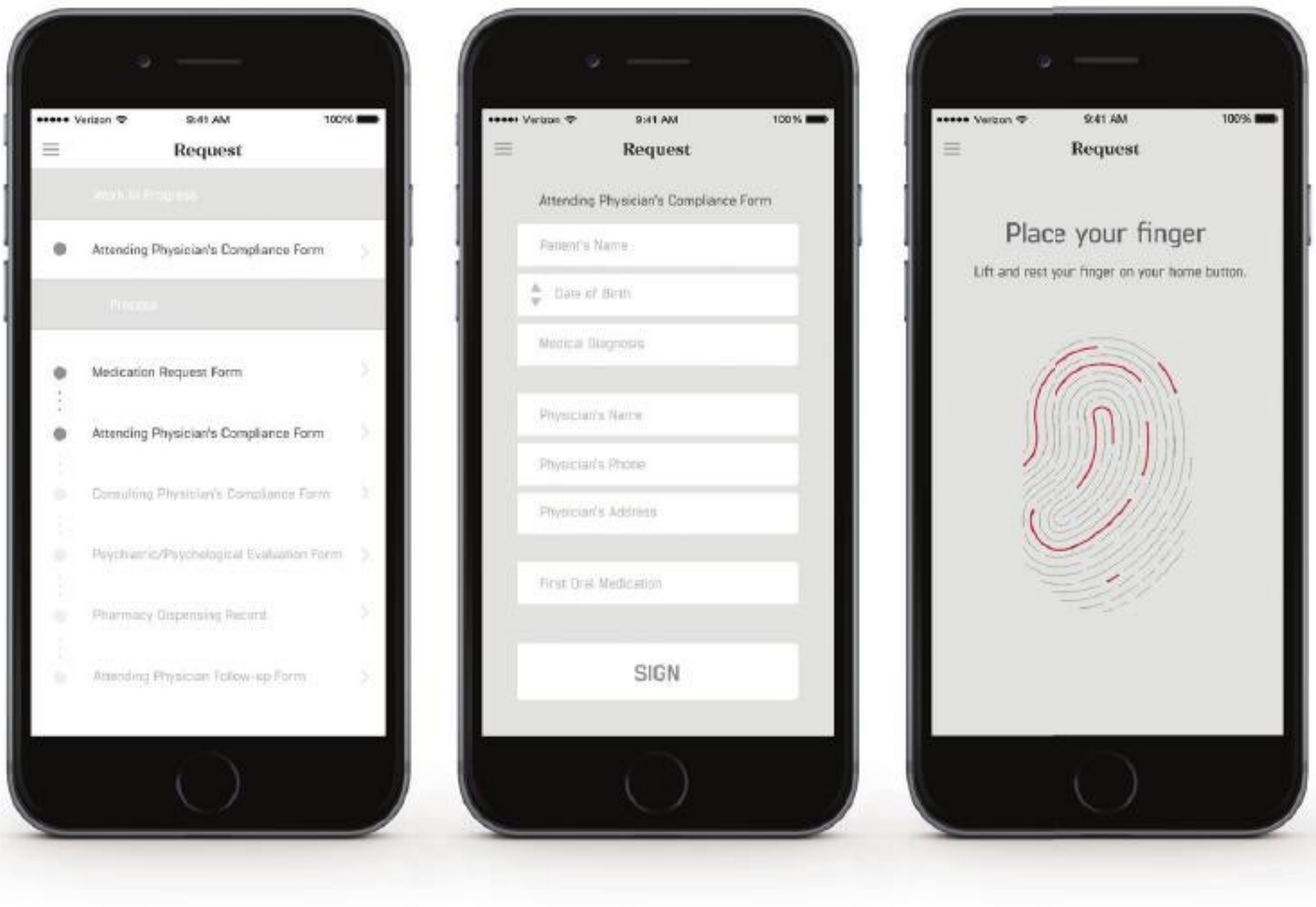
Some argue that holding the hands of a dying patient who has a plastic bag over her/his head is assisted murder. I've heard the same argument from at least three people during my interviews. Margaret Dore, a lawyer and activist who is against legalized assisted suicide, said that by holding the person's hands, you are removing the option for the person to regret their actions and take the plastic bag off their head, which is exactly what prosecutors during the Final Exit Network court cases argued the exit guides were doing. But the idea that the exit guides held the patients' hands to make sure they carried out the act is absurd. They held their hands to provide comfort and support in their final moments. Although there is no clear statute making it illegal to hold the hands of a person who is committing suicide using a plastic bag, it remains a gray area in the law that involves the risk of being prosecuted.

To mitigate that kind of situation, I made Safe Distance, an object that reminds people to keep a safe (and legal) distance between hands and not to hold the entire hand. Touching fingertips are not going to add any force that would prevent the person from moving their hands and taking off the bag. The object negotiates what is a safe distance between two people during the process of committing suicide using a plastic bag. I think of this piece as a commentary object more than a functional product. If it were to become a functional product, it would mean we had made a serious decision as a society to restrict compassionate gestures toward the dying.

Consent

Consent is an app that allows patients to file legal documents for receiving physician-prescribed suicide. There is a pile of paperwork required on top of the living will and durable power of attorney for health care. If you don't have someone guiding you through the process, you and your family have to figure it out on your own as you move forward. Today, in Oregon, all the forms have to be physically signed and mailed to Oregon Health Authority Center for Health Statistics. I thought if we can digitally file taxes online or using an app, why not other legal paperwork? The Consent app itself is a digital version of all the documents, and it allows a patient's family members and doctors to be connected so that everyone is in sync with what is going on. They can sign the documents using a fingerprint identity sensor on their smartphones.

After I visualized this concept, I realized it may be a good idea to get everyone involved in the process of prescribing lethal medication, but the intention of the law was to enable aid in dying, not to make it an easy way out. When I showed Consent to my subject matter experts, some of them wondered if this app's intention was to make the process easier for people to go through with assisted suicide. I think it is to some degree, but it is predominantly for people who have already chosen the path. I don't think more people would choose assisted suicide all of a sudden because the paperwork is now easier. One of the main points of Consent is also to inform family members and doctors about when the patient is receiving the prescription and when he or she is planning on taking it. Consent is a place where everyone is informed of the patient's decision.


Verizon
9:41 AM
100%
Request
Work in Progress
Attending Physician's Compliance Form
Process
Medication Request Form
Attending Physician's Compliance Form
Consulting Physician's Compliance Form
Psychiatric/Psychological Evaluation Form
Pharmacy Dispensing Record
Attending Physician Follow-up Form
Request
Attending Physician's Compliance Form
Patient's Name
Date of Birth
Medical Diagnosis
Physician's Name
Physician's Phone
Physician's Address
First Oral Medication
SIGN
Request
Place your finger
Lift and rest your finger on your home button.

fri[end]

The original concept of fri[end] was as an app that connects capable and incapable committers so that the former can assist the latter to commit suicide. The current assisted suicide law requires that patients take the legal medications themselves to hasten death. But patients with severe spastic quadriplegia are often incapable of feeding themselves. That leaves them limited options for ending their life. They require the assistance of others, but anyone who enables them to commit suicide can be charged with murder.

So the original concept for fri[end] was to provide an option for incapable committers while at the same time protecting their family members or close friends who would otherwise be putting themselves at risk of getting arrested. I imagined that capable committers and incapable committers could work together and assist one another as death mates so they could both achieve their peaceful death.

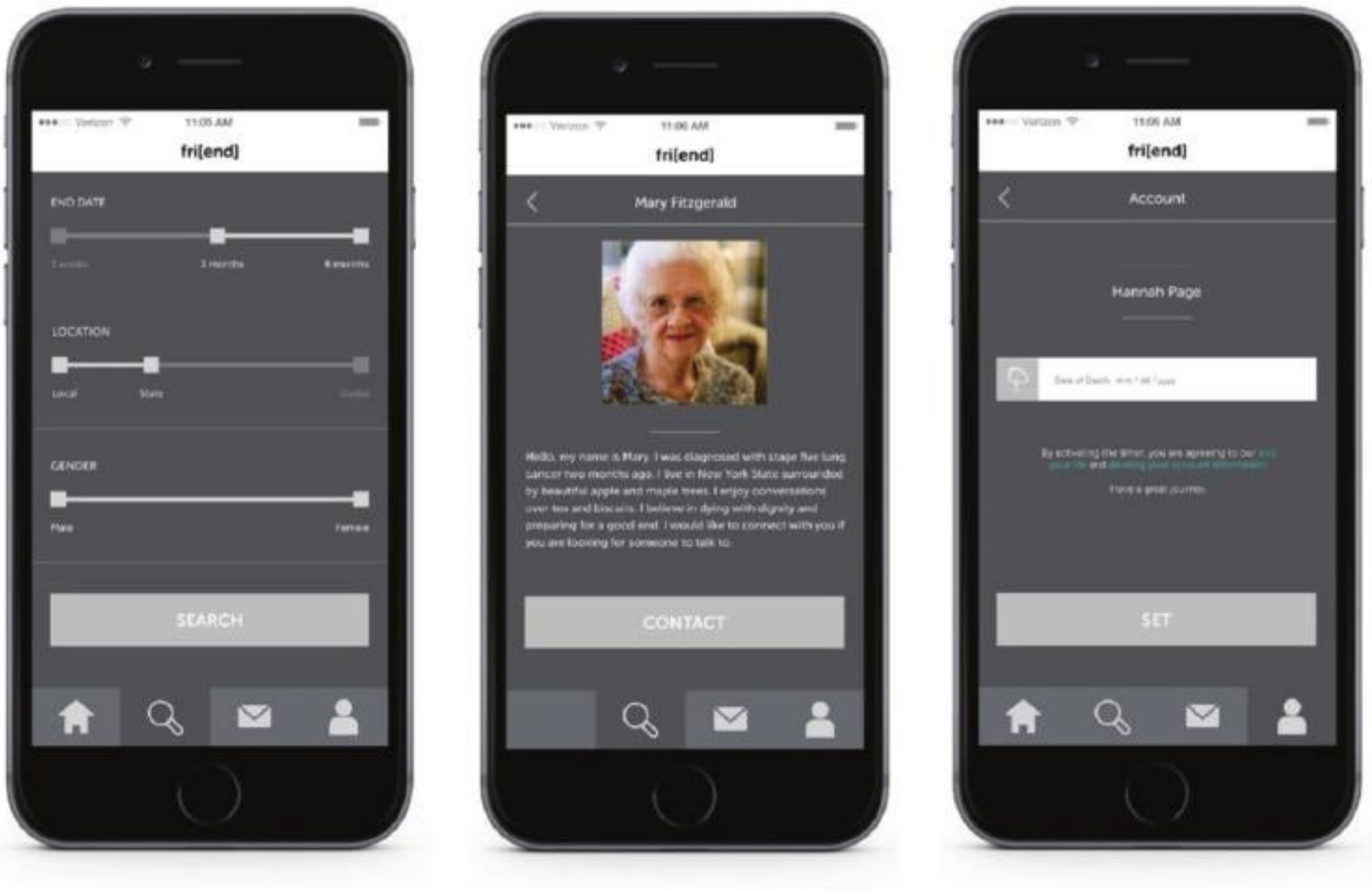
It works like Meetup.com for patients with a terminal illness, an irreversible illness, or quadriplegia. To ensure the safety of the service, fri[end] requires patients' medical records and a letter of intent when they sign up. Once committers are approved by medical professionals, they can tap into the network of people like them. Committers can search members by narrowing down when and where they prefer to die, and read about other members' stories to see if they want to contact them. It offers incapable committers, who might otherwise be forced onto life support equipment, a way out. When a capable committer helps an incapable committer to commit suicide, the law is no longer a concern since the capable committer is going to end his or her life soon too. Right before they decide to end their lives, they can set the timer in advance to delete their accounts.

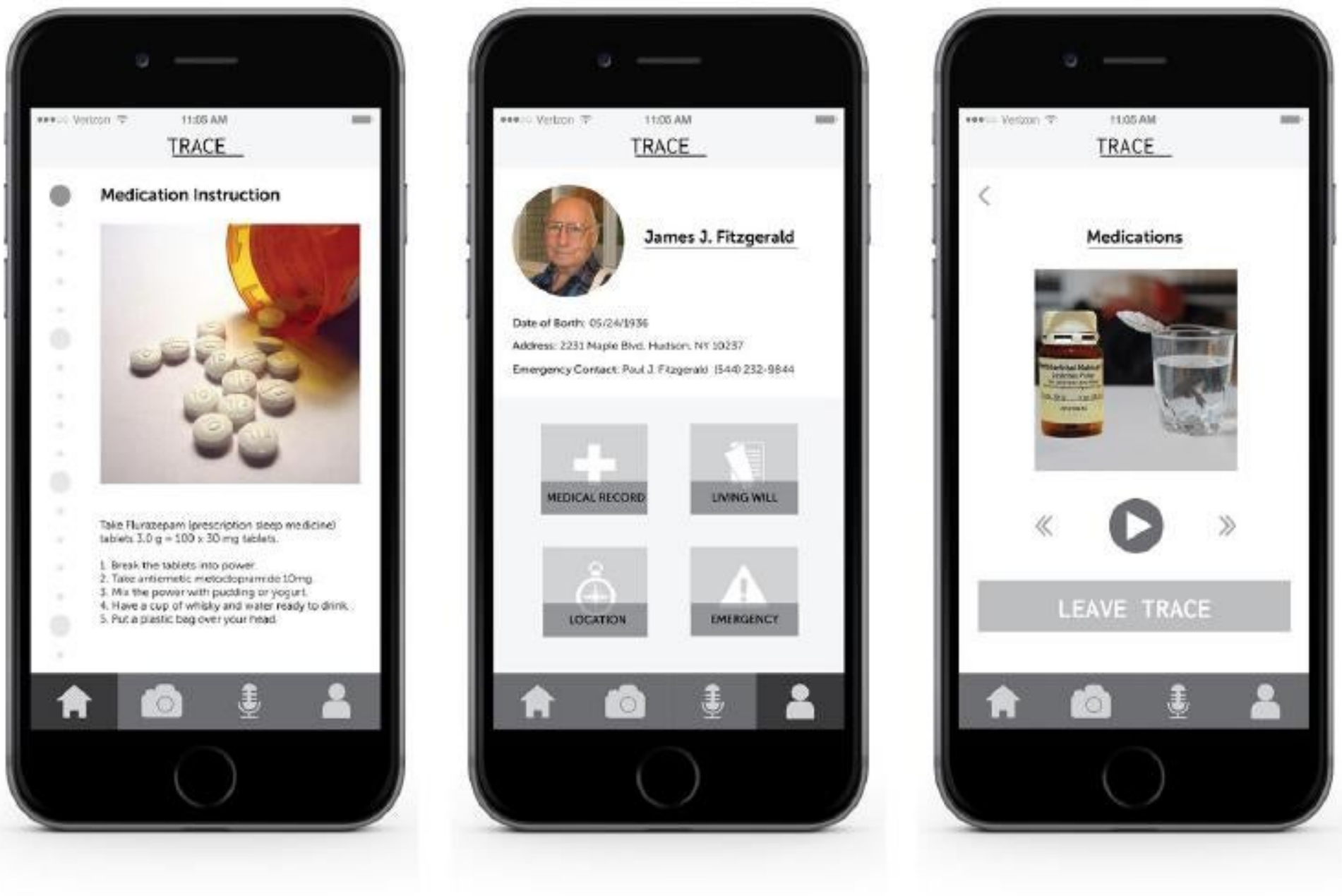
After I showed the wireframes and the concept to my potential users, I learned that the idea is interesting but logistically difficult to carry out. The feedback was that trying to "schedule" two individuals' death seems incredibly hard. A potential user said, "Let's say I was a capable committer. I probably won't decide when I'm going to end my life until the very end. Maybe a week or two weeks in advance. But you never know because it is all up to my body to decide." If that was the case, an incapable committer has to wait for a capable committer to decide when they are going to die so that he or she can get help and die just before that. A capable committer is unlikely to help an incapable committer to die if they still feel good and have more time to live because they don't want to risk the precious time they have left.

From that feedback, I shifted the concept from connecting capable committers and incapable committers to sharing stories and meeting people who are choosing aid in dying. This shift was inspired by a conversation I had with Stephen Soreff at Death Café New York City. Stephen is a sculpture artist in his eighties. He attended Pratt Institute when he was younger and has an art studio in SoHo. He lost his wife about twenty years ago from cancer. He goes to Death Café to meet people and have interesting conversations. We talked about art and death, humanity and wars, and many other subjects. One thing he

really took time to explain to me was the fact that the older you get, the lonelier you become. Your friends and loved one's health start to decline, and eventually they will die and leave you behind. "But just because you are old and dying doesn't mean that you shouldn't have a new relationship," he said. He actually met his two girlfriends on Match.com, and he even knew about the app Tinder.

With the fri[end] app, people can record their stories and share them with others. It hopes to foster the last relationship before death, and regardless of whether people actually meet in person or not, they can make new friends who acknowledge the end may be near.




TRACE
Medication Instruction
Take Flurazepam (prescription sleep medicine) tablets 3.0 g = 100 x 30 mg tablets.
1. Break the tablets into power.
2. Take antiemetic metoclopramide 10mg.
3. Mix the power with pudding or yogurt.
4. Have a cup of whisky and water ready to drink.
5. Put a plastic bag over your head.
TRACE
James J. Fitzgerald
Date of Borth: 05/24/1936
Address: 2231 Maple Blvd. Hudson, NY 10237
Emergency Contact: Paul J. Fitzgerald (544) 232-9844
MEDICAL RECORD
LIVING WILL
LOCATION
EMERGENCY
TRACE
Medications
LEAVE TRACE

Trace

The current U.S. law states that in order to be eligible for physician-assisted suicide, a patient has to be eighteen years of age or older, a resident of Oregon, Washington, Vermont, or California, capable of making and communicating health care decisions for him/herself, and diagnosed with a terminal illness that will lead to death within six months. That means patients with dementia are considered mentally incompetent and therefore ineligible.

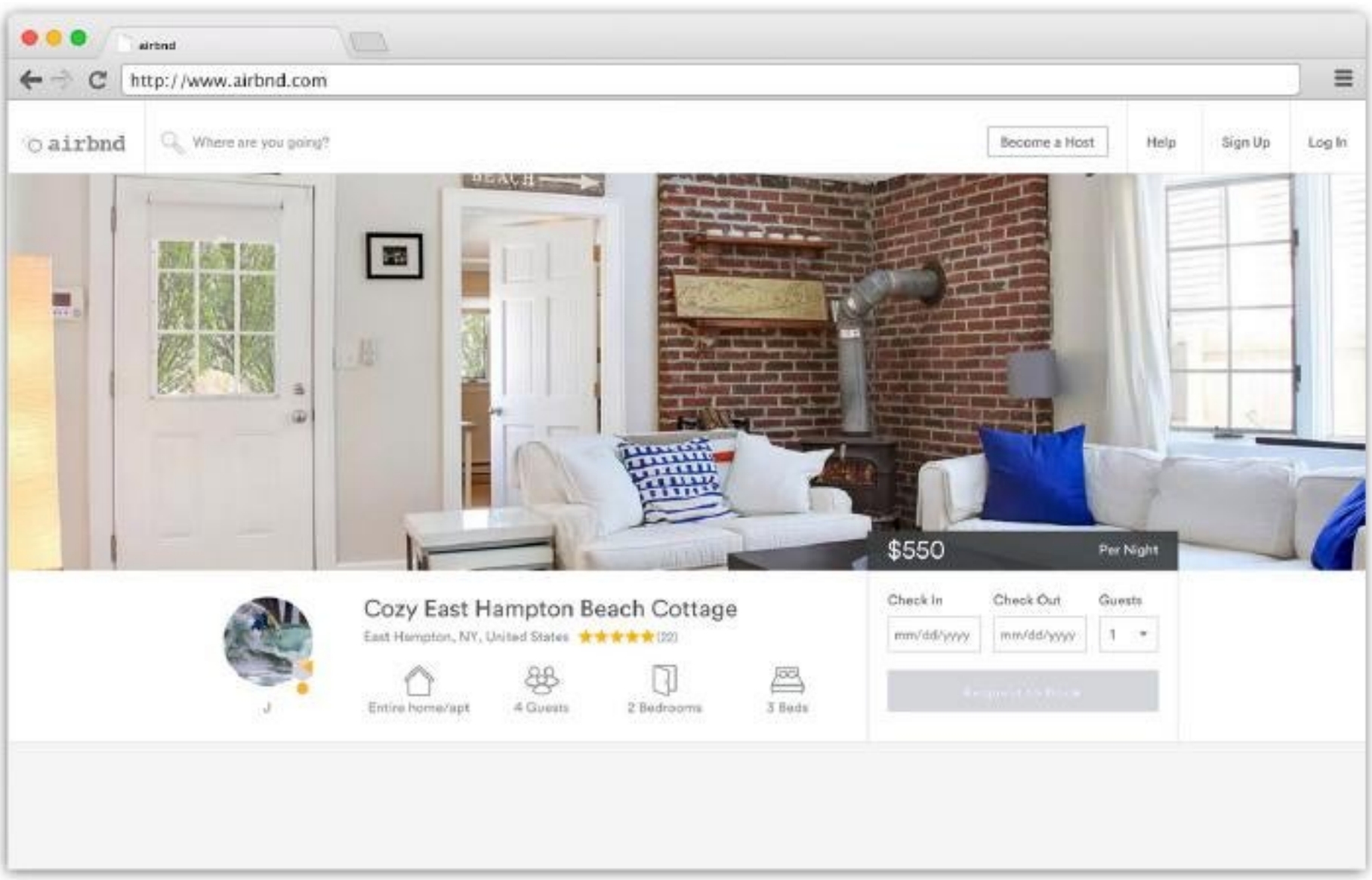
A naturopathic physician and acupuncturist at Integrative Naturopathic Medical Centre, Dr. Eric Posen, shared a tragic story associated with mental illness. A woman who was a strong activist for legalizing assisted suicide in British Columbia suddenly got diagnosed with Alzheimer's disease, but it was too late for her to legally make her end-of-life decision, and she ended up not being able to die the way she wanted. So the problem is that some people with dementia prefer to end their lives while they are still mentally and physically competent. But if they wait too long, sometimes it is too late to legally make that decision. Then they end up living out lives they don't want.

To provide a backup plan and a sense of agency for patients with dementia and their family, to choose death instead of an undesirable and lingering life, I created Trace, choosing the trace you leave behind.

Trace is a service that arranges an alternative exit plan for the mentally ill who want to end their lives before their disease completely takes control of their minds. People with dementia need a backup plan in case they become incompetent before they can carry out the act. With the help of experienced attorneys, Trace helps patients write their living will for their chosen death. With patients' trusted family members and friends, it makes sure that patients' requests will be carried out smoothly. When patients become mentally incapable and their trusted family members or friends agree it is time, we provide them with the patients' will and instructions.

Trace also comes in a mobile app format. The app allows for the patients to leave themselves instructions on how to carry out the act in case their minds get cloudy. They can photo document step-by-step instructions of their chosen death and leave voice memos. The information syncs to family members' smartphones so that everyone is on the same page at all times. The app also functions as a place where patients can update their legal documents such as their living will and power of attorney for healthcare through experienced healthcare and property attorneys. Trace charges reasonable service fees and offset the cost to patients through private donations and passionate volunteers who care about an individual's desire to have a dignified death.

The expertise in understanding the behavioral problems associated with dementia, the ability to navigate legal boundaries for receiving aid in dying, and access to passionate volunteers makes Trace a new type of dying consultancy for patients with dementia and their family members.


airbnd
http://www.airbnd.com
airbnd
Where are you going?
Become a Host
Help
Sign Up
Log In
$550
Per Night
Cozy East Hampton Beach Cottage
East Hampton, NY, United States
Entire home/apt
4 Guests
2 Bedrooms
3 Beds
Check In
Check Out
Guests
mm/dd/yyyy
mm/dd/yyyy
1

Airbnd

In thinking about planning for death, I thought of places where we spend our last moments. According to a 2005 Centers for Disease Control data sheet, nearly 70 percent of Americans die in a hospital, nursing home, or long-term-care facility despite the fact that more than 80 percent of Americans want to die at home.[1] Most people who choose physician-prescribed suicide die at home surrounded by friends and family members. Then, I thought, what if we opened up the possibilities of choosing where we die and planned for it just like we plan vacations?

Airbnd (AirBed and Death) is a play on airbnb. It is a website where people can list, find, and rent lodgings for your death. All the places listed on Airbnd are equipped for hospice care and the assisted suicide process. If you have a last wish that you want to die in a wood cabin in Vermont, you can book a place through Airbnd and the host will be prepared to receive you and your friends and family to spend the final days of your life.

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1 "Worktable 309. Deaths by Place of Death, Age, Race, and Sex: United States, 2005." Centers for Disease Control. April 10, 2008.

Full Moon

Thinking about assisted suicide as an enterprise, I imagined a company, Full Moon. It provides comprehensive end-of-life services and products to people who are looking into medically justified suicide. Trained professionals can step in at any stage of the dying process. In an interview I did with a man who was involved in assisting his friend to die, he told me that the process was very secret and no one was supposed to talk about it. And that made things harder for everyone. He even said that if there was a company that offered services to guide them through the process, they would have paid immediately. Another insight that I learned from him is that there are so many moving parts to the dying process such as taking care of bank accounts, sorting out legal paperwork, planning the funeral, and many other things. They had to find out what they needed to do as they went through the process. I believe that is where Full Moon service providers can help.

We have wedding planners and funeral directors as professions, but not really a dying consultant that specializes in medically justified suicide, other than organizations like Compassion & Choices and Final Exit Network. And no organization I could find provides comprehensive service offerings including everything from providing information about the aid-in-dying option to organizing funerals and post-death events. In recent years, we started to see more and more death doulas. Like birth doulas, death doulas don't play a medical role. They work in concert with doctors, nurses, and other healthcare professionals but don't replace them. The terms can vary, as do the roles—alongside death doulas, there are death midwives, death coaches, and end-of-life guides, among others.

While some step in earlier or later in the death and mourning process, all aim to provide practical and emotional support at the end of life. A death doula is usually engaged closer to the act of dying itself, helping those at the end spend their final moments as they choose. They may help the patient make sense of their life story or provide mental comfort by being there for them. Mourning doulas are more likely to support families after a loved one has died, and a death midwife or a home funeral guide's role is to assist the dying and their families in planning a meaningful funeral.

At Full Moon, people can find someone who can wear multiple hats so that a dying person and their family members can work with one person closely throughout the process. To visualize what Full Moon may look like, I created a campaign for the company in a form of a billboard and newspaper advertisement.

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onfirm order
Every step of the way.
For a comprehensive end of life service, visit www.fullmoon.com
FULL MOON
,000 Ltrs of fuel
, up to four 20'
eck cargo. With an
wo-position crane and
he vessels will also be
urvey and ROV work,
diving operations and all other offshore supply and support operations. In crew transfer mode, the craft operate at speeds of over 30 knots. The first of these vessels will be at Seawork 2013.
last year and returned in
sign a Sales & Service
y Agreement. Chief
eting Officer Terry O'Connor
gh our relationship
installation on Gardian XI on the Seawork pontoons. Order value? 300% more than the cost of exhibiting.
Cheetah Cat handed over

Every step of the way.
Visit www.fullmoon.com for a comprehensive end of life service.
FULL MOON

Speculative Futures

Why Future

We all imagine the future, and from time to time we wonder if the future we've envisioned is preferable to our current reality. Imagining the future is something designers in particular do on a daily bases. We think of a scenario that has yet to happen and design an object, service, or interaction around that particular moment that may or may not happen. By visualizing those futures, I believe we can start to have a conversation about decisions we make today.

Anthony Dunne and Fiona Raby talked about the importance of dreams and designed objects that function as ideas and not as tools to solve problems. Design can be used as a catalyst for discussion and debate. Instead of predicting or forecasting what is about to come, they asked "what if" questions using design.[1] A futurist, Stuart Candy often talks about the future and the plurality of possibilities in his blog. Since we don't know what could happen in the future, Candy and other futurists believe that we should consider many possibilities instead of trying to predict a future.

In thinking about futures around assisted suicide, I imagined a cultural landscape in a utopian future and a dystopian future.

1 Anthony Dunne and Fiona Raby, Speculative Everything: Design, Fiction, and Social Dreaming (Cambridge, Massachusetts: The MIT Press, 2013).

Utopian Future

It has been one hundred years since the first state in the United States, Oregon, passed the Death with Dignity law. Today, every state in the United States allows doctors to legally prescribe lethal medications to people with terminal or irreversible illnesses, or severe mental illnesses. People over seventy-five also have access to a lethal pill as long as immediate family members are informed and a short waiting period is observed regardless of the patient's physical or mental health. The government has invested in research on mental illnesses and how they affect rational decision-making. Assisting people in committing suicide is no longer a crime and it is widely understood by the general public.

Old rules and beliefs from traditional religions are fading into history, and most people believe in end-of-life choices regardless of their religion. The Catholic Church and organizations opposed to the idea of assisted suicide no longer have as much money and power as they once did to influence lawmakers. One-third of the population in the United States choose to end their lives using lethal prescriptions or injections, which contributes to reducing the cost of unnecessary end-of-life medical expenses for the family members, Medicare, and Medicaid. Elderly people over the age of sixty-five account for about 9 percent of the total population, and people over seventy-five can now go to an end-of-life store to purchase lethal drugs and products for their final exit.

You will see family members talk about how they want to die and plan for their best death casually anywhere you go. Planning for one's death is deemed as important, if not more important, than one's wedding. There are death planners, people who specialize in death and dying, providing services and support for those in need. Individuals can choose to die while doing their last wishes, such as skydiving or taking a trip to the Himalayas. Some people even plan for their "deathmoon," which married couples take before their scheduled death together. When you turn seventy-five, the government issues you a special totem that states you now have the freedom to choose a peaceful death. If couples decide to exit the world together, they can apply for a pair totem that makes sure that their bodies stay together after their chosen death.

The general economy has been stable, and the end-of-life market is growing more than ever before. Retired citizens get great retirement benefits and they are well taken care of by society. If you are a lonely elderly person, there are groups of people who can support you for your remaining time even at the moment of your death. People are aware of the environmental consequences of cremation, so more and more people choose to get their bodies turned into compost, which provides nutrients for the earth.

Dystopian Future

It has been one hundred years since Oregon became the first U.S. state to pass the Death with Dignity law. Today, every state legally allows doctors to prescribe lethal medications to people with terminal illnesses or irreversible illnesses, and severe mental illnesses. People over seventy-five also have access to a lethal pill provided immediate family members are informed and a short waiting period is observed regardless of the patient's physical or mental health. Assisting those who want to commit suicide is no longer a crime and it is widely understood by the general public; however, the line between assisting and forcing someone to take her or his own life has gotten blurry.

The desire to end one's own life and have control over the manner in which you die is widely accepted and understood, but some people abuse the law and try to kill or harm others. Senior citizens become the main source of lethal pills flowing into the black market and exported overseas.

Some people have started to fight against freedom in choosing death because there have been abuses of lethal drugs. Organizations are formed to ban assisted suicide or implement strict regulations. Some people argue that "Pills don't kill people, people kill themselves." The heated debate over the morality of the freedom to pursue peaceful death has become the new gun control issue in this last quarter of the century. People march toward their state courts with signs saying "Freedom is killing our children" and "We are at war with suicide epidemics." You see articles in the new frequently about young people ending their lives due to depression, temporary sadness, or social troubles because they found a relatively easy way to access suicide products and lethal medications. Sometimes you even hear about teenagers role playing and pretending they are going to kill themselves as a joke but actually ending up dead.

Because the medical costs for treating diseases are so high, family members are persuading their terminally ill, irreversibly ill, or mentally ill family members to hasten death. The freedom to choose death is one of the main reasons life insurance companies invest in the development of a mental state swab. The product is widely being used by forensic scientists or doctors to measure the mental state of the dead. The swab reveals whether the person was conflicted about their decision to end his or her life or if it was a completely relaxed decision made of their own free will. The swab comes out to different shades of purple to indicate the level of the deceased's distress at the time of death. The darker the purple is the more stressed they were about their decision.

The underground economy for cheap crack-like versions of lethal medications for suicide has been growing, especially after the 2072 market crash. More and more people are getting depressed and choose to end their lives peacefully regardless of age. Those who are poor and depressed often try to find a way out by killing themselves. They turn to their street drug dealers in hopes of obtaining new types of lethal drugs mixed with sleeping pills. The quality of those medications is not trustworthy. Not only do people fail to commit suicide, but they are left with brain damage and other unwanted consequences. Five percent of total hospital patients are the victims of consuming some type of un-

regulated lethal substances. They often have physical and mental disabilities. It is very hard for the government and health officials to track where those dangerous substances came from. The only thing they can do is warn and educate people on the street about the dangers of false lethal medications. Some concerned citizens develop a small tool that allows people to check if the drugs they have purchased from the corner deli actually have the strength and active ingredients to achieve death. People can purchase them at local drug stores or order parts online to assemble their own personal quality control device.

Fictional Dystopian Newspaper

To visualize this dystopian future where the slippery slope that we worried about for legalizing assisted suicide has become the reality, I created a fictional newspaper that may exist in that future.

The future USA Today newspaper's main article on the front page is about how the use of drugs in aid in dying has become the next gun control battle. The article reports that protesters, concerned that the bill will eventually prohibit doctors from prescribing pentobarbital and secobarbital, march toward the Massachusetts State House. People are worried because if the bill gets passed, some will lose their right to choose assisted suicide. Family members of terminally and irreversibly ill hold signs saying, "Don't Take Away Our Dignity" and "Pills don't kill people, people kill themselves."

Because in this dystopian future many people try to commit suicide using various methods, I imagined a product that would be advertised in the newspaper.

The product is called the Last Aid Kit. Similar to the first aid kit we have today, it contains products that can help people who have attempted suicide and survived. The kit contains things like medications and a portable oxygen mask that can be used to treat failed suicide attempts.

A14

One in thirty people fail in commiting suicide. Prepare yourself.

More information at www.lastaidkit.com

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FALLING
John Paul III and John XXIV to be de-canonized Sunday

IN LIFE
Marlo Thomas on how woman can start over

105 kids rescued from a suicide pact

Depressed teens across the U.S. met online and planned their death ▸ FBI: Take the issue 'out of shadows' 3A

Online TODAY

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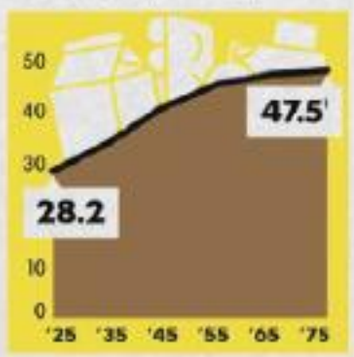
USA SNAPSHOTS®

Food stamp use rises

Enrollment in the federal Supplemental Nutrition Assistance Program (SNAP), in millions



JOHN ANDERSON FOR USA TODAY

Pentobarbital / Secobarbital
The Next Gun Control Battle?

0.2%
The percentage of people who may have been forced to take lethal medications and died since 2020.

23%
The percentage of people who choose to take pentobarbital or secobarbital as a way to leave the world peacefully.

Sharon Jayson
@Sharonjayson
USA TODAY

BOSTON — people who are concerned about the bill that will eventually restrict doctors to prescribe pentobarbital and secobarbital march toward the Massachusetts State House. People are worried because if the bill gets passed, some people will lose their rights to choose assisted suicide.

Emotions were brewing early as protesters arrived in the morning to send a strong message as senators walked into the State House. Family members of terminally and irreversibly ill were holding signs saying "Don't Take Away our Dignity" and "Pills don't kill people, people kill themselves." Shannon Watts, who was at the protest said, "we are going backwards. Restricting doctors to prescribe the pills won't solve the problem of underground lethal medications. We are targeting the wrong thing."

Pentobarbital and secobarbital are commonly prescribed to people with terminal and irreversible illness to hasten their death. They are fast-acting and have been the premier drug for self-deliverance for the last century. So, why now putting restrictions on them? Because some patients figured out a way to get their doctors to prescribe such lethal medications and then sell the drugs to dealers to make money. Those drugs then get sold for twice the price for people who are chronically depressed or otherwise looking for a terminal exit.

▸ STORY CONTINUES ON 3B

87%
The percentage of people who believe in the right to end our own lives in a peaceful manner,.

9%
The percentage of people who wants the government to strictly control the availability of lethal medications.

Patients' Costs Skyrocket So Does Family Debt

Mary Bowerman
USA TODAY

COLUMBUS, Ohio — Elizabeth Rosenthal had not paid much attention to the tiny spot on the side of her cheek until a physician's assistant at her dermatologist's office warned that it might be cancerous. 20 minutes later, she had scheduled her a procedure at the Columbus Skin Cancer Center, 12 miles away.

That was the beginning of her medical odyssey and financial nightmare. The procedure involved a dermatologist, an anesthesiologist, and an ophthalmologist who practices plastic surgery.

▸ STORY CONTINUES ON 4B

LUKE SHARRETT FOR USA TODAY

WWII Veterans Are Still Homeless

"The plan" by the U.S. Department of Veteran Affairs is far behind schedule

Olga Rudenko, Doug Stanglin and Tom Vanden Brook
USA TODAY

WASHINGTON, D.C. — Despite efforts since 2072, when the U.S. Department of Veterans Affairs launched its plan to end veterans' homelessness, nation's numbers have dropped less than 4 percent, now totaling about 2 million – while the demand for services is growing.

GREGORY TEJADA FOR USA TODAY

The federal government is pouring billions of dollars into housing and support services for homeless veterans and their families. One reason more people are seeking help is that outreach workers are finding more homeless and at risk veterans and bringing them into the system.

"At the current rate of progress, the goal of ending veterans' homelessness will not be achieved by 2082."

New York state Sen. James Libous, a Republican from Binghamton. His bill to restrict the use of budget for welfare passed the state Senate in June last year.

GREGORY TEJADA FOR USA TODAY

According to to a report by the U.S. Interagency Council on Homelessness, the process of distributing money to all states in need takes time and fare distribution.

A pilot program is starting this month to help WWIII veterans who live in federally-subsidized apartments find jobs that would pay enough for them to live independently and thus make more rent subsidies available for others. The Department of Housing and Urban Development – VA Supportive Housing program, (HUD-VASH), serves a population that is not easily employable – chronically homeless people who have disabilities and terminal health conditions need ongoing support to live in their apartments.

STATE-BY-STATE 4A MARKETPLACE TODAY 6D PUZZLES 6D USA MARKETS 5B WEATHER 8A WHAT TO WATCH 7D YOUR SAY 7A

Mental Swab

Mental Swab is a medical tool that might be used in the dystopian future where sick people end up going through with assisted suicide because they have been persuaded by their family members to do so. I imagined that forensic scientists would need a tool to test the mental state of a deceased person to see if the individual died in peace according to his/her own wishes or if there is an indication of stress from being forced to choose assisted suicide. The product is used to take a sample from the brain through the nose. The long curved form allows the swab to reach the brain without damaging the body.

NAME: Janett Jane Wyman
M X F
Date: 01 / 22 / 2075
Amsure CTX

Explored Work

Throughout the process of working on my thesis, I looked at assisted suicide through four different design lenses: speculative products, services, mobile applications, and experiences. I think of design lenses as literally different ways to look at a topic. Using these lenses as leverage points, I designed what is the most advanced yet acceptable design for today's audience. I also explored assisted suicide methods and tried to redesign the forms of products used in self-deliverance. All of the work was inspired by true stories that I heard during my interviews with my target audience and assisted suicide documentaries.

Visor Hood

People should spend a considerable amount of time thinking and choosing the right way to die. Ideally, they share their decisions with their family members and close friends and get moral support. They also should ask their doctors for help before deciding to end their life by self-deliverance. If their doctors refuse to help them end their lives citing personal beliefs or legal dilemmas, they are left with the options of using a plastic bag aided with sleeping pills or inert gas to achieve a peaceful death. After careful consideration, if a person decides that using the plastic bag method is right for him or her, this product may be suitable.

This visor-style plastic bag hood is designed to make the self-deliverance easier and as comfortable as possible in the process. Once a person reaches a rational decision that the pain is unbearable and no physicians agree to help, he or she can use sleeping aid medications and a visor hood. The product was inspired by the conventional method of using a plastic bag over a person's head to reassure death. The conventional plastic bag can get uncomfortable because it can get sucked into the mouth and nostrils as the patient breathes in and out. To remove that discomfort, the visor hood creates space between the nose and mouth and the plastic bag. The bag is designed to just go over a patient's head for effectiveness. The bag used in this method should not be loose or much bigger than a person's head; it takes longer and may not be as effective if the bag is too big.

Capable committers should practice putting the visor hood on before the real attempt. It is important to get used to putting on the visor hood and fastening the ribbon by the neck. It is usually recommended to put the hood on soon after you take the medication, depending on the strength of the chosen sleep aid. You don't want to wait until you are half asleep to try putting on the hood as you may lose consciousness. To make sure it is done properly, having someone you trust by your side may be reassuring; they can guide you in case you get nervous. The visor hood is available in three sizes—small, medium, and large—to accommodate different head sizes.

Couple Hood

As I read many stories of people choosing to end their life, I couldn't help but think about the idea of going together. Sometimes, we hear news stories about elderly couples that die within a day or month of each other. This phenomenon is called "broken heart syndrome" also known as stress-induced cardiomyopathy or takotsubo cardiomyopathy. It occurs when someone loses a close partner or spouse and experiences intense emotional or physical stress. It can cause rapid and severe heart muscle weakness, especially in the elderly. All those stories are sad, but also very touching at the same time. The phenomenon is a clear indication that many elderly couples may even prefer simultaneous death.

Such incidents are by no means uncommon among married couples or those who have been together for a long time. The fear and stress of being left behind and alone are something so unbearable that some elderly couples choose to die together. It almost doesn't matter if both of them are in poor health or if only one of them is. If they feel that they have lived full lives and want to leave this world with their loved one, such deaths, in my opinion, should be up to the individual to decide. We shouldn't promote or romanticize the idea of double suicide, but we shouldn't condemn it either.

Peter and Pat Shaw as a young couple. “The Big Sleep” The Age.

Peter and Pat on the day they died. “The Big Sleep” The Age.

One fine afternoon on October 27, 2015, scientists Pat and Peter Shaw died in a suicide pact in Victoria, Australia. Their daughters opened up to the media about their parents' lives and their plan to die together. The Shaws had been members of Exit International, a pro-euthanasia group that teaches peaceful methods for people to end their own lives. They enjoyed life very much. Throughout their time together, they engaged in hiking, climbing, and skiing. They also loved classical music, literature, fine wine, and robust conversation. They were big supporters for political and environmental movements. As a young scientist, Peter Shaw conquered a mountain in Antarctica on a 1955 research expedition, for which he received a Polar Medal and was immortalized on a postage stamp. The mountain is named after him as well. As they got older, they had to endure the increasing troubles of old age, in particular their diminishing health. Pat was a biologist who taught medical students at Monash University, but she was determined to avoid hospitals, nursing homes, palliative care units, and any institution that would threaten their independence in old age. Facing the unavoidable decline in health, the elderly couple decided on their end-of-life plans, informing their three daughters that they had chosen October 27, 2015, the day after Pat's eighty-seventh birthday, to enter the "big sleep" together.

Their daughters tried to cheer them up and visit them as often as they could, but they seemed to be tired all the time and had difficulty moving around and doing things that they used to be able to do. The night before the day, the family had a last supper of sorts together at home, but the Shaws were no longer interested in good food. Peter wrote his suicide note on September 17, describing himself as "sane, quite good-humored, and not at all depressed." Pat's handwritten note was done six days after with the family's Christmas pudding recipe for her daughters on the side. The next morning, they dressed and made their bed early. Peter had a small breakfast, but Pat didn't eat anything because she wanted to keep her stomach empty. With the soft morning sun shining down on their backyard, the family sat down and enjoyed their native gardens. Their daughter Anny described their state as "very relaxed and ready to go." Their other daughter Kate said, "It was all so normal. I just started laughing at the [surrealism] of it . . . and took out my phone to take some photos—something I never do." The three daughters left the house around noon because assisting, aiding, or abetting a suicide is punishable by up to five years in jail in Victoria.

Pat didn't want to die by herself, so her plan was to take a lethal medication first. Peter was supposed to leave her in their bed, walk downstairs, and through the hallway into the living room where they spent many hours together. He had his equipment set up in his shed so that he could walk through his backyard one last time. The three daughters went to a café and walked around the beach where they grew up, and they waited. They said that there is never a good way to lose your parents. They were scared, not because by the time they got back home their parents would be gone, but because there was a chance one of them wouldn't be. No one knows exactly what happened during the last moments of their lives. When the three daughters came home around 1:30 p.m., they went upstairs and found their mother lying in bed. Their father was reclining in a chair in the shed. Neither showed any signs of life. The plan had worked, and the Shaws seemed to have gone peacefully into the big sleep.

What happened next was a little bit disturbing. The three daughters called their parents' doctor, expecting him to sign a death certificate for them. But he was busy that afternoon, and told them that two deaths required a call to triple zero (000), the primary national emergency number in Australia. From that call, the outside world started to come in. Within minutes, paramedics arrived, their lights flashing outside of their home, followed by police cars. What had been a very private matter suddenly became a public spectacle. They had to explain that their parents intended to die and did not want to be resuscitated. Eventually, the homicide squad arrived at their doorstep and what was a peaceful family home became a crime scene of sorts. The sisters had to go to the police station to make statements, but no charges were pressed.

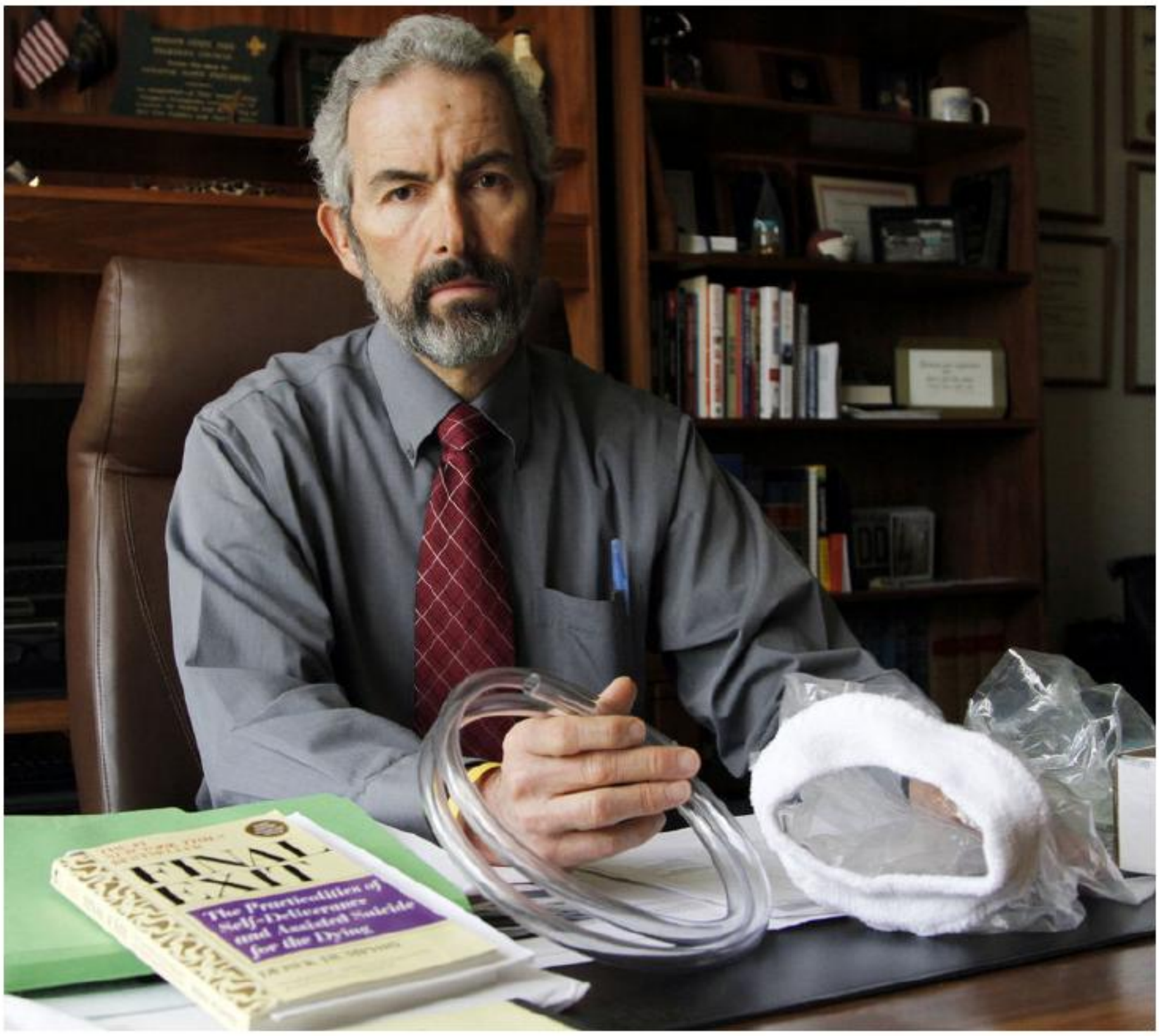
Reflecting on what had happened, their daughter Kate said, "It shouldn't be so difficult for rational people to make this decision." The full story "The Big Sleep" is available online at The Age.[1]

To respect the decision of a devoted couple reaching the end of their lives, I created a double exit hood. The hood is inspired by Sharlotte Hydorn's suicide hood. Sharlotte Hydorn was a ninety-one-year-old retired teacher and widow who made and sold helium hoods from her house in California, mailing them to anyone who requested one. She sold each hood for $40. She'd sold more than 1,300 kits to people across the United States and abroad.[2] But one day the FBI knocked on her door. She was arrested for selling suicide kits and not paying taxes.

Similar to how Sharlotte Hydorn's hood was designed, the double hood uses the helium method. Breathing inert gas like helium leads to loss of consciousness and eventually a peaceful death in fifteen minutes. This method is said to be a fairly simple and painless way to die because your body reflexively wants to breathe but doesn't really care what it breathes. When you breathe pure helium, or any other inert gas such as nitrogen, you don't actually feel any sensation of suffocation. You simply fall unconscious after a minute or so, and within fifteen minutes, you are gone. Two people put the hoods over their heads, one person turns on the gas, and the other person seals the gas inside of a plastic bag. It requires partnership and the participation of both parties to achieve death.

1 Medew, Julia, "The Big Sleep" The Age, January 2016

2 "91-year-old California Woman Pleads Guilty to Selling Suicide Kits and Not Paying Taxes," Daily News, December 3, 2011.



Oregon state Sen. Floyd Prozanski shows a "suicide kit" consisting of plastic tubing and a plastic bag with collar that fits over a person's head. Authorities in Oregon have begun cracking down on the contraptions that hook up to a helium tank and allow people to gas themselves to death. The Associated Press

Balloon time
NET CONTENTS:
14.9 ft³ (0.42 m³) mixture of
air containing not less than
How To Inflate
Storage
For Best Results
Float Time
Balloon time
CONTENIDO NETO:
14.9 pies³ (422 L) mezcla de
que no contiene menos de
THE #1 NEW YORK TIMES BESTSELLER
FINAL EXIT
The Practicalities of Self-Deliverance and Assisted Suicide for the Dying

Freedom

In 2005, John Welles, a fiercely independent sixty-six-year-old man, ended his life with his .38-caliber revolver in the garden near his house.[1] He was dying from prostate cancer. I was inspired by the story of John Welles and people like him who preferred to spend their last moments outdoors enjoying nature. Freedom is a portable tank carrier that provides committers an option to die in nature or somewhere that requires portability. The minimal design allows patients to carry only one tank of inert gas and a medical mask.

When I was talking to people about where and how they want to die, several people said that they would like to die in the woods, on a beach, or by a lake. So I thought of making an object that would allow people to be more mobile. Inspired by scuba diving gear, I designed a tank carrier with a medical mask. After making this version using the inert gas method, I realized that it calls for a service of some sort to take care of the body afterword. It seems that this product needs to come with a plan to discover your body after death in nature or somewhere outdoors.

---

1 Written, produced, and directed by Miri Navasky and Karen O'Connor, narrated by Will Lyman, "The Suicide Plan," PBS FRONTLINE, November 13, 2012.

FULL MOON

Passage

Finding the "magic pills" is key to achieving a peaceful death. In a state like Oregon, patients can request a lethal amount of barbiturates to end their lives. Residents of other states where physician-prescribed suicide is illegal, however, must obtain drugs from their doctors in increments, slowly acquiring enough for a lethal overdose.

There are many types of drugs that are deadly if ingested in great quantities; even aspirin can be lethal in large amounts. The most commonly used drugs in self-deliverance are painkillers, sleep aids, and morphine. Those drugs are easier to get prescriptions for depending on a patient's health conditions. Some painkillers and sleep aids require the use of a plastic bag, taking a large dosage, or a combination of both. Morphine is slow-acting but lethal if patients haven't acquired tolerance through previous use.

Patients really need to be careful about what drugs they use for their exit plan because some drugs have nasty side effects that will present themselves if the overdose fails to result in death. Side effects include blindness, deafness, brain damage, etc. Adding any of those conditions to whatever the patient is already experiencing would be disastrous. More details on drug dosage and use for self-deliverance is available in Final Exit.

Barbiturates like Nembutal and Seconal are very difficult to obtain. They are fast-acting and extremely lethal medications if overdosed. They are said to be the best drugs for self-deliverance and are the most common prescriptions written by physicians under Death with Dignity laws.

Pentobarbital, commonly known as Nembutal, is a short-acting barbiturate. Veterinarians often use it as an anesthetic agent or euthanasia drug. In humans, it is used in hospitals for specific circumstances, like to induce a coma in brain-damaged patients or to stop seizures in patients for whom other medications proved ineffective.[1] Barbiturates put the brain to sleep and slow down brain function. They act as central nervous system depressant and can produce mild sedation to complete anesthesia.[2] When people ingest enough barbiturates, they stop breathing and their hearts stop pumping.

The price of Pentobarbital in liquid form was about $500 until 2012, then it rose to between $15,000 and $25,000.[3] The price increase was caused by the European Union's ban on exports to the United States because of the drug being used in capital punishment. The practice has been completely abolished in Europe and the European Union holds a strong and principled position against the death penalty. Due to the drug shortage in the United States, fourteen states introduced Pentobarbital as one of their three-drug execution cocktails or one-drug protocol between 2010 and 2012.

As a result, many international pharmaceutical companies that don't want to be associated with executing inmates have refused to export the drug to the United States. Users then switched to the powdered form, which costs between $400 and $500.[4] However, the use of Pentobarbital in capital punishment has restricted its availability for medically justified suicide. The fact that there is capital punishment in the United States has made aid in dying more expensive. While Pentobarbital isn't the only drug used in assisted dying, it has a major advantage: It's about ten times cheaper than secobarbital, another drug often prescribed for aid in dying.

Secobarbital is similar to Pentobarbital. It is used short-term to treat insomnia, or as a sedative before surgery. It comes in 100mg capsules, and in order to achieve death, patients need to take one hundred capsules broken apart to produce about three tablespoons of powder (10g). The legal dose of the medication costs about $3,000 to $5,000. According to GoodRX.com, a website that allows you to compare prices of drugs in your local pharmacies, thirty capsules of Seconal costs approximately $950 to $1,000 in New York City today. These are only estimates as prices and availability change. Recently, one patient was forced to seek funding for her secobarbital from a Washington foundation that helps cover end-of-life costs.[5] People who hope to use Death with Dignity laws are becoming the victims of capital punishment.

---

1 Pam Belluck, "What's in a Lethal Injection 'Cocktail'?," The New York Times, April 9, 2011.

2 Ananya Mandal, MD, "Barbiturate Mechanism," News-Medical.net, May 26, 2013.

3 "Death with Dignity FAQs," Death with Dignity website.

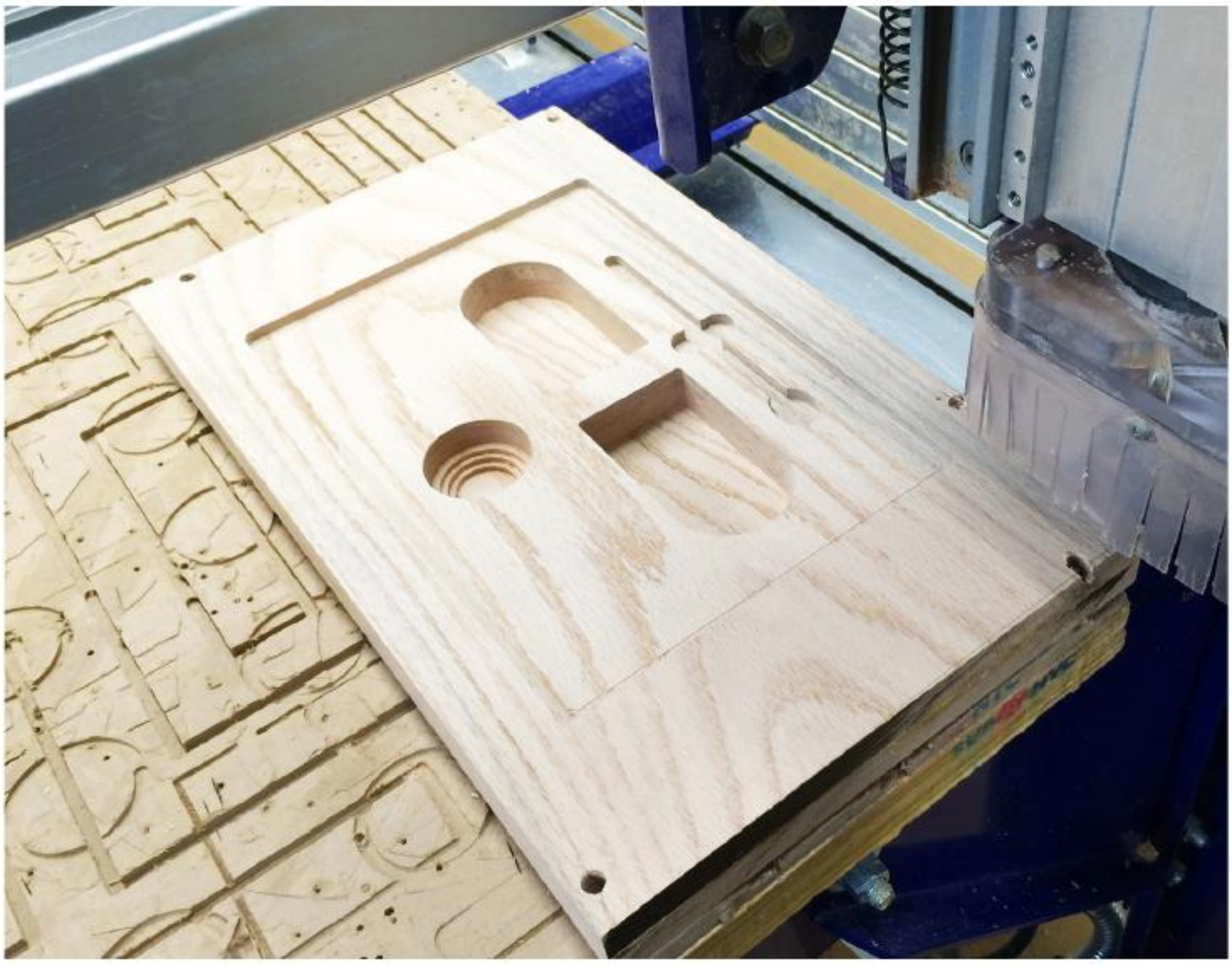
4 Kimberly Leonard, "Drug Used in 'Death with Dignity' Is the Same Used in Executions," US News, October 16, 2015

5 Nigel Jaquiss, "Penalized by the Death Penalty," Willamette Week, May 20, 2014

In the documentary How to Die in Oregon, several patients took Seconal as their final medication. Volunteers from Compassion & Choices broke one hundred capsules apart to make ten grams of Seconal power. Then they mixed that with six ounces of water to create the lethal cocktail for patients, while family members and friends said their final goodbyes. One gentleman who drank the medication said at the beginning of the film that it tastes like wood. It seems to me that because Seconal comes in the form of a capsule, the act of breaking them apart and making the cocktail becomes almost like a ritual for reaching the end. It needs to be precise, without any mistakes. The Seconal cocktail is the last thing he/she will ingest into his/her body. The act of drinking it leads to the deep sleep that they wished for.

To make the process of preparing the medicine more of a ritual, I created Passage. It is a set of a cup, mixing spoon, and tray for preparing your last drink. Inspired by the Asian tea ceremony and tea sets, the product ritualizes the practice of making medicine. The components are made of wood to resemble the taste of the cocktail. The materiality of wood suggests that it is not practical for multiple uses because wood can be scratched easily and is not as long lasting as plastic, glass, or ceramics in serving food and drink. The form of the tray suggests the placement of capsules; unopened capsules on the right and shells to the left. There are spaces for the cup and mixing spoon to sit in when preparing the medicine. The cup is designed to encourage the user to drink its content in one shot. The bottom of the cup is completely rounded so that the user cannot put it down. Once you remove the cup from the tray, the cup needs to be held. The Final Cocktail can be used by family members or caregivers and then given to committers, or if committers themselves are capable of doing the preparation, they can put the set on their lap and use it. I believe that well-designed objects that are both aesthetically pleasing and functional can transform this last action before death into a meaningful time for appreciating life and what is about to come.

smartwater
Marathon
SECONAL SODIUM



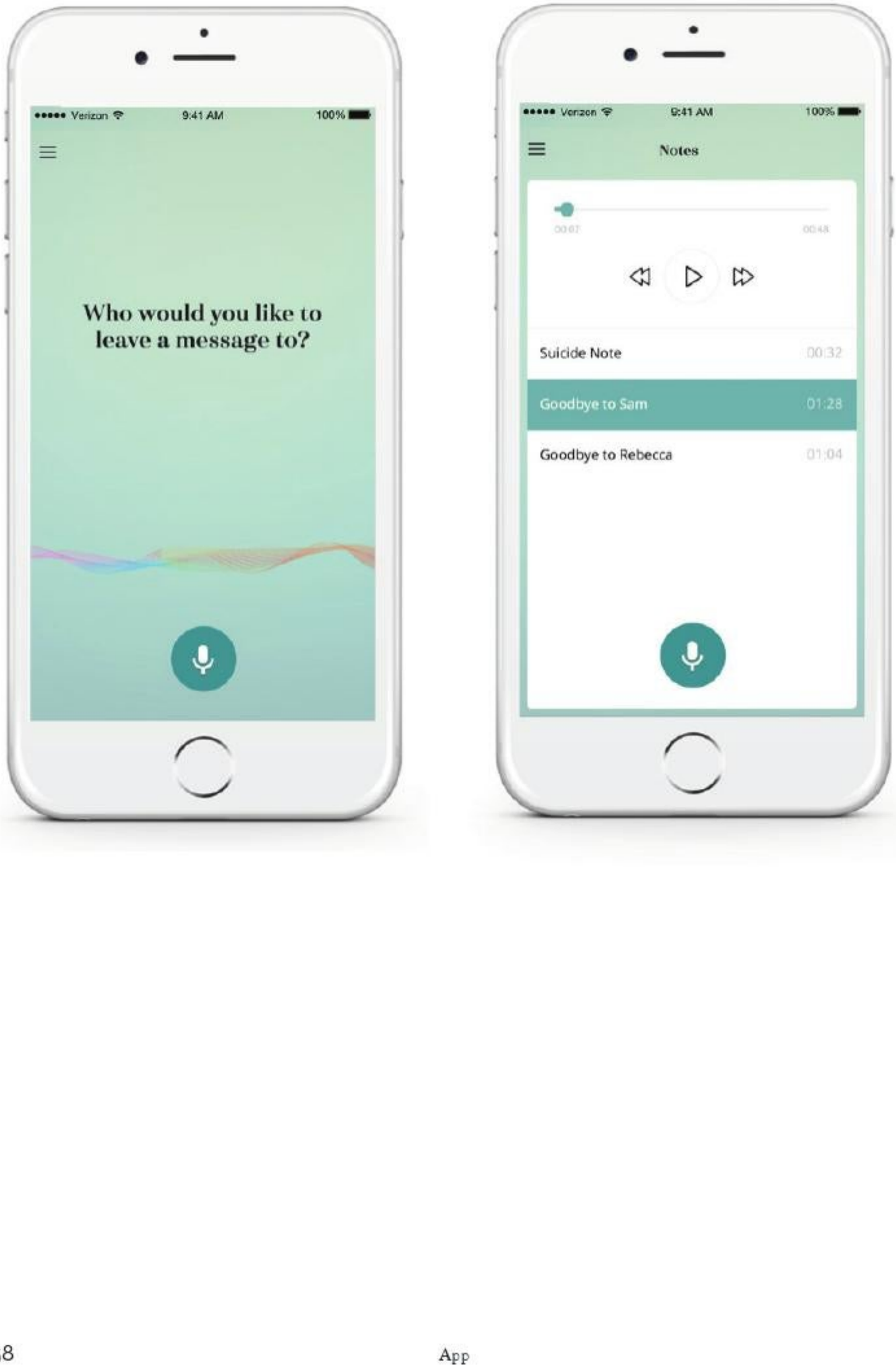
Coda.

Coda is a mobile app that utilizes a conversational user interface. It lets users write goodbye notes to their friends and family and send them out when the users are ready via voice dictation. Conversational user interface is a machine-user communication program modeled after human-human conversations. The app becomes a virtual assistant for organizing and delivering users' farewell messages.

The concept was inspired by the stories I heard during my interviews. People had to call many of the deceased's friends and acquaintances to let them know that he or she had passed away. Most of the time, it is the job of family members who are left behind. Sometimes they have to literally go down a list to make phone calls. I've heard a case in which some people got really upset not because they heard the sad news of their friend passing but because they didn't know that the deceased decided and planned to exit the world and didn't tell them about it.

When we can decide when and how we are going to die, we can carefully plan and prepare for that moment. Coda allows the dying people to craft their last message to friends and distant family members. Users can speak into their phones to write goodbye letters in their own words to people who should know about his or her death. When the time comes, users can say, "I think it is time," and the app would double check if it is a final goodbye. If the user says "yes, final goodbye," then the app asks the user when they want to send the message out: in five hours, tomorrow, or in two days. Coda reduces the burden on family members who are left behind to sort out who should know about the news and who should hear the news first. With Coda, users can draft letters as if they are talking to that person they are writing to.

Verizon
9:41 AM
100%
Coda.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Who would you like to leave a message to?
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Notes
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Suicide Note
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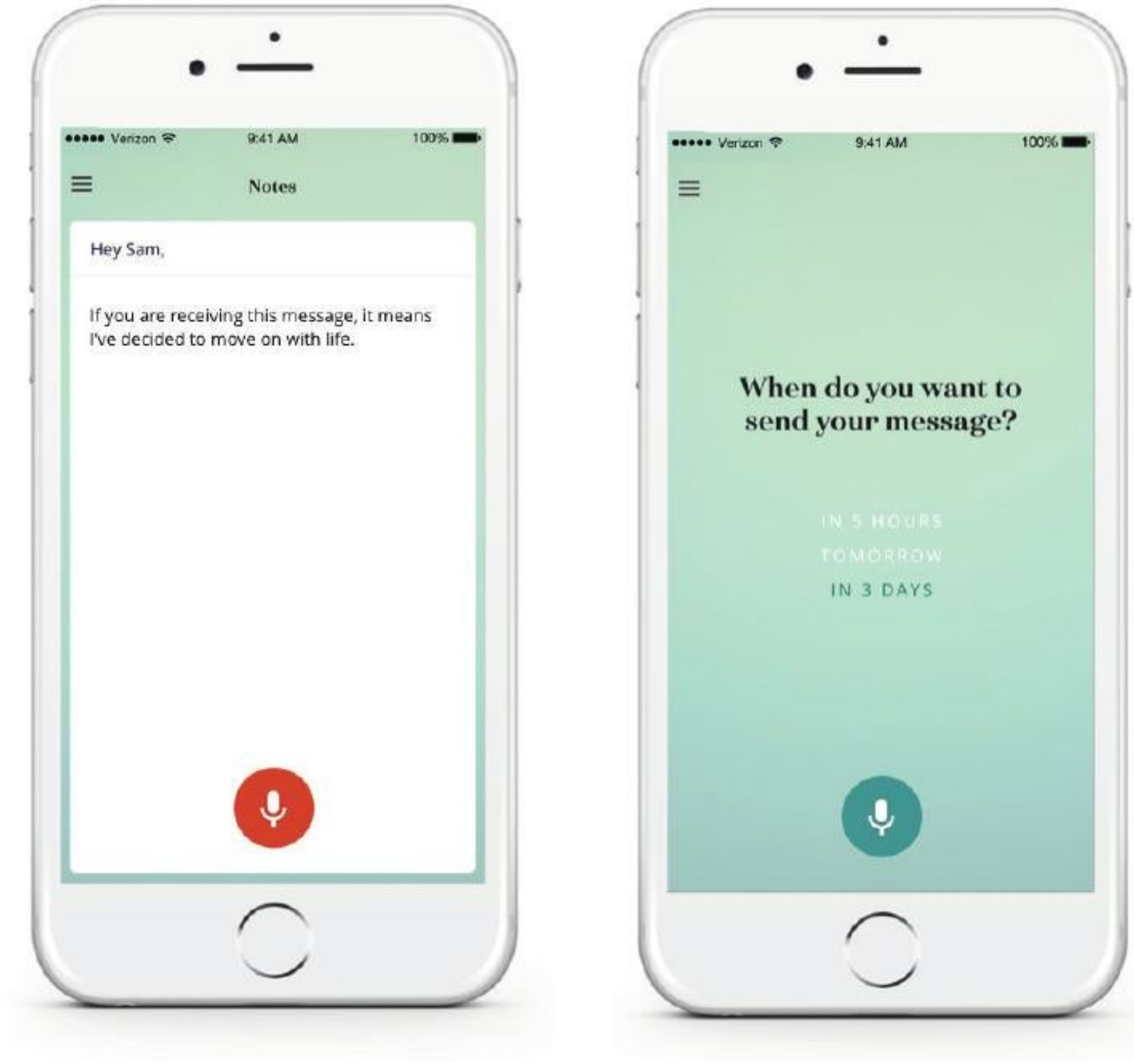
Goodbye to Sam
01:28
Goodbye to Rebecca
01:04


Verizon
9:41 AM
100%
Notes
Hey Sam,
If you are receiving this message, it means I've decided to move on with life.
Verizon
9:41 AM
100%
When do you want to send your message?
IN 5 HOURS
TOMORROW
IN 3 DAYS

CompassionAid

Some dying people who don't meet the legal criteria take matters into their own hands using information and methods available to them. But death is not that easy and quick to achieve. Some take longer to die, and each person has a different tolerance to medications. Without professional guidance, when something goes wrong during self-deliverance or in preparation, people have no one to turn to. Under such circumstances, those who are assisting someone to die (often a trusted family member or friend) are under enormous pressure to help their loved ones. They cannot ask for help or seek emergency advice on how to achieve death. They cannot call 911 because they don't want the police or paramedics to get involved.

Inspired by the story of what happened to Richard and his friends, I designed CompassionAid, a twenty-four-hour hotline that provides assisted-suicide-related consultations for people in need. It is a safe place to reach out to for support from trained professionals who can help reduce some of the stress. The phone number will be listed on the social media pages of Final Exit Network, Euthanasia Research and Guidance Organization (ERGO), Compassion & Choices, and Final Exit Book so that people know about it before going through the process. When people call a toll-free CompassionAid number, they will be connected to a trained professional anonymously.

The call is routed to states where there is no law that says aiding, abetting, assisting, or counseling suicide is a crime. Those states are Nevada, Utah, Wyoming, and North Carolina. This way, CompassionAid operators and users avoid breaking the law. The service is free of charge because an offer of payment or other promise of compensation or reward is an element of solicitation; therefore, it can be seen as a crime. Instead of charging for their service, CompassionAid incorporates a gifting model to sustain the operation, which means clients can donate whatever amount they wish after they receive the service. It is a voluntary payment through the CompassionAid website.

Throughout the interaction, a trained professional listens to every detail of what the caller is saying about the situation and calmly asks for necessary information about the patient's condition. To better assess and provide guidance, CompassionAid operators will have a manual of possible scenarios and best solutions to different issues. Having someone to talk to during a stressful situation can be a great source of comfort. CompassionAid operators are knowledgeable about self-deliverance and the emotional states of people who may call. In addition, they have personal experience with assisting their own loved ones so it is easier to establish trust with the caller. Our expertise and experience in guiding and helping people through difficult situations make us the only place where people can feel safe asking for help and getting answers to assisted-suicide questions any time, day or night.

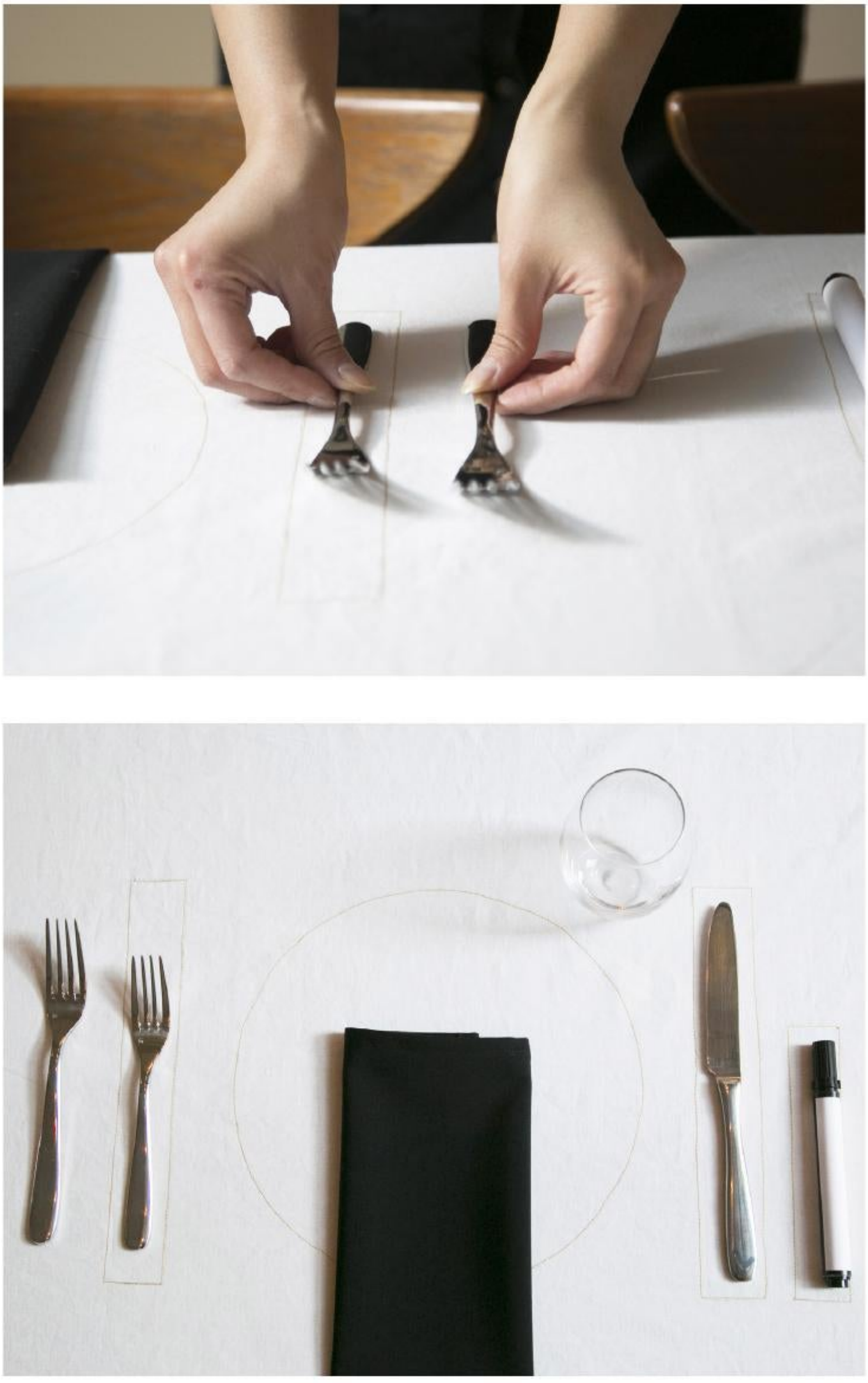
12:30 AM
(800) 222-0456
mute
keypad
speaker
contacts

The Farewell Party

Looking at assisted suicide through the lense of experience, I was interested in the planning for death and how we can reframe or reimagine the way we approach death. I wanted to create an intimate experience in which a small group of people can talk about death and dying and celebrate a person's life before it is too late.

The Farewell is a dinner party celebrating the life of Crysdian Daniel Keith Llemson in preparation for his death in the future. He is a forty-six-year-old gay man living in New York City. Crysdian has been HIV positive since he was eleven years old, and last year, he was diagnosed with a brain tumor. He told me that he had thought about death many times. He has gone through surgery and chemotherapy for his tumor, but he fears the condition could get worse one day.

This dinner party was for him to celebrate his life with his close friends and talk about how he wants to die when the time comes.



The party took place on the chilly evening of March 20, 2016. We rented a cozy apartment on 14th Street with a beautiful wooden dining table. At the party, we served three of the meals that brought Crysdian back to his childhood. Throughout his entire life, whenever he was left sad or sick from medications, these were the comfort foods that would make him feel better. The appetizer was pickled herring. His very first childhood memory of food was of having herring. Born to a Scandinavian family, fish was in almost every meal, and his grandmother used to make pickled herring at home. For the main course, we served meatballs. The dish reminded him of the times when they used to get together as a family and make dinner. As a child, mushing up meatballs was the only thing he was allowed to do in the kitchen and he enjoyed doing it. Even after he had grown up, he would eat meatballs with his father whenever they had a chance. For dessert, Crysdian baked a red velvet cake. He remembers having home-baked cake at birthday parties, and he wanted to bake it for his guests in celebration of this important moment.

At the dinner, Crysdian told the guests that when the time comes, he prefers to have control over his death and is considering assisted suicide as an option for himself. He wants to go peacefully, just like falling asleep, when it is time to go. Throughout the dinner, they shared their personal stories of dealing with death and dying and how they feel about aid-in-dying. There were some heated discussions about the issue and what dignity means for people with terminal illness, but at the end, all of the guests came to understand Crysdian's choice and his feelings. A big part of this experience was to provide a space for people to share the love they had for one another. Many times we say things after someone is gone and we wish we had said it while he or she was here. Sometimes we don't even get to say "I love you" to a person we really care about and we regret it for a very long time. In case anything happens to Crysdian in the near future or far off in the future, he wanted to use this dinner party as a way to tell his friends why he cared about them. The party provided them an opportunity to really open up and share their feelings. He'd invited each of his friends with a written invitation in addition to a handwritten personal card telling each of his friends why he loved them as a way to thank them for coming to the party. The card became a physical token for the guests to take away from the entire experience.

Toward the end, Crysdian asked his guests to use the fabric markers that were placed on the table as a part of the place settings to write their biggest fear about death and dying on the tablecloth. So that if anything happens to him, he can take the tablecloth with him and the guests will no longer walk out of the door with that fear because they know that Crysdian will hold that. The entire experience was an emotional journey. We shared laughter and tears.

Looking back at the experience, I realized the project started as a way to celebrate Crysdian's life, but at the end it became a means for the guests to think about their own wishes for the end of their life. They saw the tablecloth almost like a mirror to reflect and imagine their own ending. All the guests said that they had never really thought about their own deaths and how they want to leave this world even though they had seen deaths in their lives. The fundamental concept of this project was very simple. I created a space in which Crysdian and his friends could have conversations about death and celebrate their friendships. I had no control over how their conversations would flow or how the guests would react to this uncommon and rather strange party. But I was extremely touched by the reactions of the guests and by how Crysdian led the conversation throughout the evening. The time I spent planning this event with Crysdian was one of the most eye opening and heartfelt experiences I have ever had. I cannot thank him enough for being so kind and open-minded. His passion about life and death truly changed my perception of how I want to approach my own life and death.

If this project were to move forward, I would love to find a way to create a template for this experience so that more people can do this on their own without me being present. From the feedback I got from the guests, I think the duration of the party can be much longer so that they can really go deep into the conversation and unpack some of the nuances they were trying to convey about what dying with dignity means to them. Crysdian also wished that he could have spent more time writing letters to his friends rather than a quick thank-you card for the guests to take away.

Pain
Physically Diformed
To die Ugly
To die alone
To die with so
much anger,
and hate.

Being alone
No longer able
to help myself + others
No having u in my life
losing my children
before I die

I'm scared of
my loved ones suffer.
Pain is also a part of it.
I'm scared of having
regrets in life...

Pain
Physically Deformed
To die Ugly
To die alone
To die with so
much anger
and hate

Looking Back & Forward

Throughout my journey into the world of assisted suicide, I learned a lot about what it means to plan for death while appreciating the life we have now. Navigating through the law is difficult and complicated, but the law can be changed and is changing as we speak. My hope is that one day we all have the option to end our lives in a peaceful way if that is what we desire. Work that I have shared in this book is my contribution to the death with dignity movement, and I truly hope more people, especially designers, will look at the issue and use the power of design to tackle this controversial and difficult topic.

Personal Responsibility

One thing that I have not really talked about previously is that I was and probably still am walking on the edge of breaking the law myself. I was designing and making essentially what people would call "suicide hoods" that could actually work. I say "could" because the bag is sealed; I have not tested the hoods on anyone for obvious reason, though I did ask volunteers to wear them for documentation. In the eyes of the law, even that can be seen as aiding or abetting suicide, even though that was not my intention. There may be some who will believe I deserve to be put in jail for my designs, and I suppose they could make a legal argument. But I have a strong point of view on this issue, and I wanted to express that through my work. I acknowledge that my work may influence and provide people means to choose suicide, but that is not my intention and is essentially beyond my control. If someone who is not terminally ill sees my work and decides to commit suicide, I would be deeply sorry. I really would. But if my work means something to people who are suffering at the end of life or to my mother, who wishes to have options for herself at the end, I think I can live with that. Such is my commitment to this thesis.

Possible Impacts

I see this thesis having multiple impacts on today's society–social, political, economical, and environmental. The social consequences may be that this thesis is a small step toward recognizing our fundamental right to die. We all have the moral right to choose what we want to do with our lives, and I believe that we have the right to end it as well. Through my work, I hope to remove the negative images associated with assisted suicide and shift people's perceptions about how we should die. The ideal political impact of this thesis in my opinion is pretty clear: I hope more states and countries will legalize assisted suicide and change the policy that punishes people who help their loved ones end their suffering. This policy change should not be about recommending death to people with terminal illnesses but enabling people to choose the way they want to die, and physician-prescribed suicide should be one of them.

The economical impact of my work is that if we legalize assisted suicide, we could potentially make a significant change in the nation's healthcare costs. Keeping a person who is dying and wants to die alive can cost incredible amounts of money. In 2008, Medicare paid $50 billion just for basic medical bills during the last two months of patients' lives, and that was more than the budget of the Department of Homeland Security or the Department of Education.[1] It has also been estimated that 20 to 30 percent of these end-of-life medical expenditures might have no meaningful impact.[2] As the baby boomers get older, the number of people needing Medicare increases and so does the bill. Denial of death has created expenses better spent elsewhere at the end of life. If assisted suicide becomes legal and social attitudes toward death shift, we may be able to save that money and put it toward something more hopeful such as education or climate change initiatives.

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1 Produced by Andy Court and performed by Steve Kroft, :The Cost of Dying," CBS News 60 Minutes, November 19, 2009,

2 Ibid.

The environmental impacts of my work is not as direct as other impacts I have mentioned above. In my design, I tried to use sustainable materials such as wood, but it is hard to eliminate plastic entirely from my design. With the couple hood, for example, plastic is necessary for achieving death. Another environmental impact that assisted suicide may have is when people choose self-deliverance or physician-prescribed suicide over staying in the ICU. I believe the energy and material consumption required for assisted suicide is much lower than the enormous carbon footprint created by prolonging life in hospital beds.

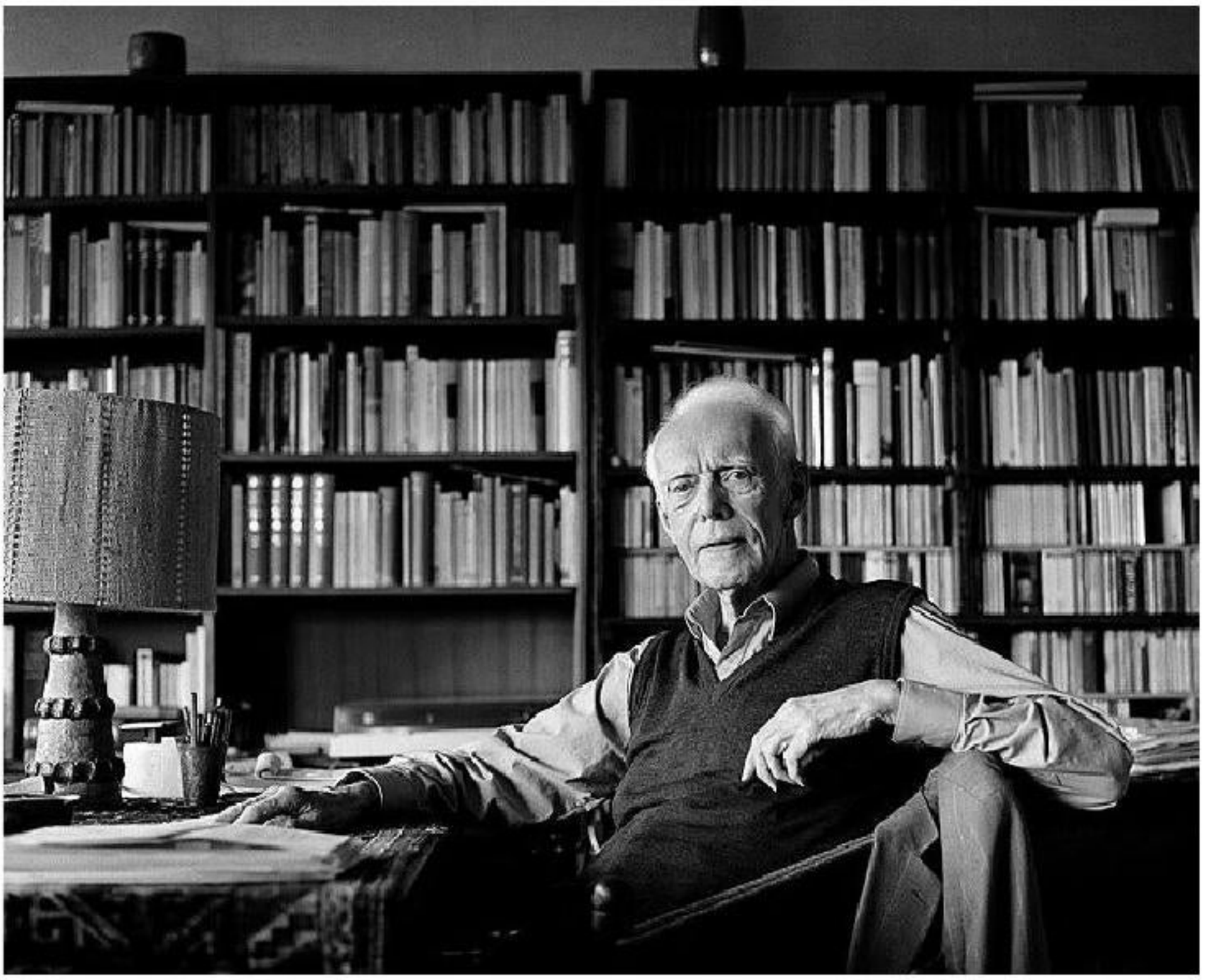
Beyond Assisted Suicide

Looking beyond aid in dying for the terminally and irreversibly ill, there is talk of the development of "Drion's pill," a suicide pill that was proposed by Huib Drion, a former Dutch Supreme Court judge and professor of civil law. He's argued since 1992 that people aged seventy-five or over, tired of life, should be empowered to end their lives in a humane manner.[1] The pill was supposed to be taken in two stages. The first pill would enable another pill to be taken a number of days after. Without the second pill, the first pill would be harmless, but combined with the second it would be lethal. The idea is that a person could take the pill on an impulse, so a waiting period seemed reasonable and sensible. So far, this has been a theoretical proposition, and no such pill actually exists. The Dutch right to die organization NVVE changed the name from "Drion's Pill" to "Last Will Pill" in 2003 in hopes of making the pill better understood.[2]

Clearly dying with dignity is not only a medical issue, but a legal and philosophical one as well. It is interesting to think about what is considered an acceptable, rational reason to end one's life. In my personal opinion, there is nothing wrong with choosing to end your life if you are beyond a certain age and feel that you have lived a full life, especially if you are alone with no family to consider. Perhaps the "Last Will Pill" will spark more thoughtful discussion about assisted suicide and end of life issues in the future.

1 Derek Humphry, The Good Euthanasia Guide: Where, What, and Who in Choices in Dying (Junction: Norris Lane Press, 2008), 20–22.

2 Ibid.



Portrait of Huib Drion, Nederlandse Vereniging voor Vrijwillige Euthanasie (NVVE)

Glossary of Terms

Active Euthanasia
Deliberate action to end the life of a person, usually by an injection of lethal drugs, performed by physicians to avoid the further suffering of a dying patient. It is illegal in most countries including the United States.
Synonyms: lethal injection

Aid-in-dying
The most neutral term to describe what advocates call "death with dignity" and opponents call "assisted suicide." It is now widely accepted in law and medicine to describe the practice of a physician prescribing lethal medication to dying patients.
Synonyms: assisted suicide, death with dignity, physician-prescribed suicide

Assisted Suicide
Providing the means (drugs or other things) by which a person can take his or her own life. The most commonly known term to describe the practice of a physician prescribing lethal medications to dying patients and the dying patients seeking a hastened and peaceful death.
Synonyms: physician-prescribed suicide, aid-in-dying, self-deliverance

Capable/Capability
The ability of a person to communicate with a physician and understand the implications and consequences of medical procedures. It also refers to the physical ability of a person to end his or her own life by ingesting lethal medications or using a plastic bag.
Synonyms: Competent/Competency

Committers
People who are terminally or irreversibly ill and have decided that they want to end their lives on their own terms. They are no longer patients because they can't really recover to a healthy condition. They are supporters of legalizing assisted suicide.
Synonyms: Dying people who have chosen aid-in-dying

Death with Dignity
An option chosen by an individual to withdraw from chronic medical therapies or to hasten peaceful death when there is little expectation of cure. It is the term often preferred by advocates to describe assisted suicide. The term contains the feeling of being able to die on your terms, your way, and on your time.
Synonyms: assisted suicide, physician-prescribed suicide, aid-in-dying

Dignity
The state or quality of being worthy of living or dying. It is a subjective concept that an individual patient has to define for him- or herself as to what they consider acceptable and honorable conditions under which to die.

Durable Power of Attorney for Health Care
A legal form by which a person nominates another person to make healthcare and medical treatment decisions if and when he or she loses the ability to communicate with physicians or understand the implications and consequences of medical procedures.

Euthanasia
A "good death," and a broad descriptive term for all acts of assisted dying. It is the practice of intentionally ending a life in order to relieve pain and suffering.

Living Will
A legal document that lets people state their wishes for end-of-life medical care, in case they become unable to communicate their decisions. People can direct a physician in writing not to connect or to disconnect life-support equipment if a procedure is merely delaying an inevitable death. It has no power after death.

Medically Justified Suicide
A concept used to describe patients who have incurable illnesses seeking a hastened and peaceful death. It is also used to describe physicians providing justification for a patient's desired death.
Synonyms: physician assisted suicide, self-deliverance

Passive Euthanasia
An option to disconnect life-support equipment without which a patient cannot live. Medical equipment can include a respirator, feeding tube, or a sophisticated drug administration. There is no ethical debate or legal issues associated with this option as long as patients have signed a Living Will and a Durable Power of Attorney for Health Care.
Synonyms: pulling the plug

Physician-prescribed Suicide
A doctor knowingly and intentionally providing a person with the knowledge, means, or both required to commit suicide, including counseling about lethal doses of drugs, prescribing such lethal doses, or supplying the drugs.
Synonyms: physician-assisted suicide, physician aid-in-dying, physician-aid suicide, physician-assisted death, medically justified suicide

Right to Die
A general term reflecting a basic belief that end-of-life decisions should be an individual choice and people should have the option to end his or her own life.
Synonyms: right to choose to die

Self-deliverance
An act of ending your own life. This method does not involve other people directly, but patients' loved ones and friends can be, and perhaps should be, present at the time of death. It is completely legal and ethical to take your own life. If patients decide to refuse any water and food causing self-starvation and dehydration, it is also considered self-deliverance.
Synonyms: suicide, medically justified suicide

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Acknowledgement

I cannot thank enough for those who contributed to and supported my journey into the world of assisted suicide. This thesis and the book couldn't have been possible without you.

“The smallest act of kindness is worth more than the grandest intention.”

— Oscar Wilde

Allan Chochinov
Gabrielle Kellner
Marko Manriquez
Alisha Wessler

Brent Arnold
Emilie Baltz
Abby Covert
Steven Dean
Janna Gilbert
Andrew Schloss
Sinclair Scott Smith

The rest of PoD faculty

Tak Cheung
John Heida
Boris Klompus

Judy Chi
Adam Fujita
Oscar de la Hera Gomez
Wan Jung Hung
Isioma Iyamah
Panisa Khunprasert
Eden Lew
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David C. Leven
Sophia Macalintal
Hedi McKinley
James Niwa
Christa O'keefe
Jessica Pierce
Kenneth Prager
Jennifer Tsung
Elaine Zhang
Michael Zhu

My mother and father

And many others who have contributed to this thesis

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Hayashi is a crazy dog mom and lover. She enjoys hiking in the woods with her energetic dog named Dragon, and she is skilled at petting her dog with one hand and pushing pixels with the other. You can follow Dragon's adventures with Hayashi on Instagram @dragon._.ballz !

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